Anthony Back
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Mastering Communication with Seriously Ill Patients

Balancing Honesty with Empathy and Hope

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MASTERING COMMUNICATION WITH SERIOUSLY ILL PATIENTS

Physicians who care for patients with life-threatening illnesses face daunting communication challenges. Patients and family members can react to difficult news with sadness, distress, anger, or denial. This book defines the specific communication tasks involved in talking with patients with life-threatening illnesses and their families. Topics include delivering bad news, transition to palliative care, discussing goals of advance-care planning and do-not-resuscitate orders, existential and spiritual issues, family conferences, medical futility, and other conflicts at the end of life. Drs. Anthony Back, Robert Arnold, and James Tulsky bring together empirical research as well as their own experience to provide a roadmap through difficult conversations about life-threatening issues. The book offers both a theoretical framework and practical conversational tools that the practicing physician and clinician can use to improve communication skills, increase satisfaction, and protect themselves from burnout.

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PREFACE

I was listening to Mrs. P explain, through tears, how unfair it felt for her cancer to have returned. I said, "You're right, and you are being very polite. This sucks." The oncology Fellow next to me looked a little surprised, but Mrs. P laughed. Later, when we were out in the hallway, the Fellow said, "I've never seen a conversation like that before. She really calmed down." What the Fellow had seen up to this point left her with some common but misguided assumptions – that she should stick to the medical facts, minimize the patient's emotions, maintain an objective distance, and hope the patient has good coping skills. I hadn't done any of those things. "What you said really worked," the Fellow said, "how did you do that?" This book is our explanation.

Who is this book for?

This book is for physicians who want to communicate better with seriously ill patients and their family members. It isn't surprising that many of us struggle as we seek to combine explaining biomedical science,

dispensing clinical judgment, and counseling about how to cope with a life-threatening illness. This book seeks to respond to that struggle. Consider this book as an advanced course for those who have some experience and want to use their time with patients wisely, find deeper meaning in their work, and protect themselves against burnout. Nurses, social workers, and other clinicians who find themselves in these situations may value techniques in this book as well.

What's in this book?

In this book, we describe a variety of communication tools and "roadmaps" that you can use to find your way through difficult conversations. In our years of teaching students, residents, Fellows, and attendings, we have found that many have either not seen a really good conversation, or they have not been able to identify what made the conversation work. Master clinicians in action with patients can be so fluid, so seamless, so responsive, that great communication looks easy. In fact, these master clinicians are collecting lots of data from the patients, drawing from a large repertoire of skills, and constantly readjusting their gestures and words. This master clinician could be you.

How will this book help me?

Adopting in your own practice the tools and roadmaps we've laid out will make you a better communicator. What do we mean by better? You'll be clearer about where your patients stand, more skillful at understanding their concerns, and more effective when you make recommendations. You'll be the kind of doctor that people want for their family and friends. And you'll develop a deeper sense of what matters to you in your clinical work because you will be talking to patients about what really matters. We think that in improving your communication you will become a better physician.

How did we develop this book?

For the past 8 years, we have taught Oncotalk, a series of intensive retreats on communication skills designed for medical oncology Fellows. In the process of creating the workshops, we realized the power of identifying key skills, providing roadmaps for conversations, and having people practice. We have been amazed at how learning a few key tools can change the way Fellows communicate. Listening to them talk about difficult topics with patients before and after their training was like observing completely different doctors. Fellows who have attended our courses tell us that these communication skills have changed how they approach patients, how they deal with emotional moments, and, most important, how they feel about their work.

Why did we write this book?

Difficult patient encounters frustrate physicians daily. When you face demanding – sometimes tragic – situations, using communication skills that are "ok" is like riding a bike with three gears – there are some hills you just won't be able to climb. For dealing with life-threatening illness, skills that many consider adequate are actually not good enough, and both patients and physicians are paying the price. To make matters worse, research on patient-doctor communication suggests that most doctors aren't quite as good at communication as they think. And even those who are aware of their shortcomings tell us they don't have confidence that they can change. In this book, we want to show you that change is possible, and you can become a better communicator. First, we describe what expert clinicians actually do when they talk to patients and their families. Second, we show what you can do to improve your practice. We highlight specific skills to emulate and offer suggestions for how to practice these behaviors. We want to raise the bar on communication skills. We want to change your idea of what really good communication looks like.

Where possible, we have grounded these recommendations in the growing literature on communication. Yet, we've consciously distilled the communication tools and roadmaps into a reader-friendly format. This is not an academic review of the literature that stresses what we don't know. Our goal is practical – to help you communicate better.

How is the book organized?

We organized the book in a progression that parallels how physicians meet patients (Chapter 2) and follows them through the course of a life-threatening illness, including talking about serious news (Chapter 3), making treatment decisions (Chapter 4), discussing prognosis (Chapter 5), managing between the big events (Chapter 6), conducting a family conference (Chapter 7), dealing with conflicts (Chapter 8), handling transitions to end-of-life care (Chapter 9), and talking about dying (Chapter 10). The last chapter (Chapter 11) will help you know what to expect as your skills improve and describes what getting better feels like. Throughout the text, we include real snippets of conversation, slightly disguised, from our workshops that provide you actual words to use.

Finally, we want to congratulate you for wanting to improve your skills. The first step in the journey is the hardest one. You have made that commitment by picking up this book.

1 TAKING YOUR SKILLS TO THE NEXT LEVEL

The challenge

Telling a mother of two that her colon cancer has returned – and it's incurable. Explaining to a schoolteacher that to continue working, she will need portable oxygen. Giving the news to an accountant with chronic hepatitis that his incidentally discovered hepatocellular cancer is unresectable, so he's off the transplant list. Explaining to a father with refractory congestive heart failure that he needs hospice.

For those of us who care for these patients, these conversations are part of the territory that we learned to navigate mostly by trial and error. Even after years of experience, we still need to take a deep breath before getting started, to prepare for a conversation that will change the life of the person before us.

Patients and their families remember these conversations like they happened yesterday. They can remember what the doctor said, often word for word. They remember whether the doctor rose to the challenge with honesty, kindness, and resourcefulness, or whether the doctor filled an awkward silence with medical jargon. They remember whether they left the visit hopeful or confused.

How clinicians handle these difficult conversations can make or break a therapeutic relationship. We have seen clinicians who take on the challenges and others who sidestep them. Most of those who steer clear of tough encounters have good intentions but don't know how to act on them. They worry they'll say the wrong thing, that the patient or family will break down or freak out, or that they are opening a Pandora's box that will take way too much time in a busy day.

How do you talk with patients and their families about balancing hope versus reality, triumph versus disaster, or trust versus suspicion? Do you wish you were more confident about where to go with the conversation? Do you feel stuck when the patient asks, "Why me?" Do you get into arguments with a son who is angry? If so, this book is for you.

Does better communication really make a difference?

Let's be honest. As interns we were taught – in the hidden curriculum – that as long as the patient was getting the right tests and treatments, nothing else really mattered. Sure, it was important to be nice to patients. But, at the end of the day, attendings pimped us about the labs, the scans, or the treatments – they didn't pay attention to whether we had explained the diagnosis in a way that the patient could understand. Their implicit message was that communication is like the cherry on top of a sundae – a nice touch but expendable.

We were misled. The research shows that communication is central to the work a physician accomplishes. Good communication improves a patient's adjustment to illness, lessens pain and physical symptoms, increases adherence to treatment, and results in higher satisfaction with care. Poor communication skills are associated with increased use of ineffectual treatments, higher rates of conflict, and less adherence. What's more, good communication doesn't just affect patients; it also

affects you. It helps you enjoy and thrive in your work. Better communication skills are associated with less stress, less burnout, and even fewer malpractice claims. Suboptimal communication creates a vicious spiral that makes us feel more like hamsters on a wheel than like healers.

Moreover, clinical practice is changing in a way that puts a premium on communication skills. With the Internet, patients have more access to medical information than ever before, and they are avid consumers of this information. In addition, advances in biomedical technology have made decision making much more complicated. Patients and families need physicians to help interpret the information and add the clinical judgment and experience that they cannot get from a Web site. Thus, communication between patients and physicians is more complex, and has more layers, because physicians must integrate a mountain of biomedical information with their patients' values, hopes, and priorities. The Internet has a place but does not substitute for a skilled, caring physician.

Can doctors really learn to communicate?

When we give lectures on this topic, one of the comments we hear most frequently is, "You can't teach communication. You pick up what you need from experience. Besides, some people are simply better at it than others." Well, it's true that some clinicians start out better than others. But communication is a skill that can be taught, and when it's not taught properly, the learning that occurs through trial and error is not always productive.

As physicians progress in their careers, they don't see how others communicate – the interactions are usually private – and they only get feedback when they've been really good, or really bad. So, most physicians settle into communication routines. These habitual patterns are not necessarily bad, because they help us routinize our world.

However, the downside is that we may charge along in our work and overlook patients' individual needs. The patient worries about quality of life and the doctor talks about survival. Or the patient wants information and the physician keeps asking questions about coping. Either way, the routine leaves patients at least a bit frustrated and, worse, feeling isolated.

Like the golfer who needs a lesson to correct his swing, clinicians need to consciously shed these bad habits. This can only be accomplished through learning some new techniques and gaining experience using them. The good news is that sophisticated research shows that physicians can indeed learn to communicate better. But not by doing the same old thing over and over. You need to see the medical encounter in a new way and make better observations about what is happening. Then you can be more intentional about what you are trying to accomplish and more versatile with a wider array of communication tools. And as a result, your patients will be more satisfied – and you will be too.

What better communication will do for you?

After our work was profiled in the *New York Times*, a physician wrote to describe his experience learning to communicate. As a young resident in the emergency room, he remembered asking his supervisor how to tell a parent that her child had died in a car accident. The attending physician's advice: "Don't let the family get between you and the door." It's a sad commentary on how physicians learn, and reminds us of the study in which oncologists cited "traumatic experiences" as the most influential source of learning communication.

Compare this to the feedback we received from one of our Oncotalk Fellows. He wrote:

It remains clear that these conversations are difficult to have. Being surrounded by bad news does not necessarily make a person skilled at delivering it with compassion or clarity. Still, I listen to myself speaking to patients and using the tools I learned during my week in Colorado. I feel less flustered and my words are less tangled; I can focus on the person across from me and find out what is needed from me in that moment – and that seems like progress.

This seems like progress to us, too. Our measure of success for skilled clinicians is that they will be more capable about finding a way through a difficult conversation. We don't promise that the conversations will always feel simple or smooth or that better communication will enable you to escape sad situations. We can say however that, many of the doctors we trained feel more engaged with their work, more connected to their patients, and get more joy from their practice. It's exhilarating to watch. We see physicians who become more flexible and more resilient and develop a greater capacity for the work medicine requires.

What's our philosophy?

Over the past two decades, we have watched waves of terminology and ideology break over the practice of medicine. Terms such as "shared decision making," "patient-centered," and "relationship-centered" have all been used in support of better communication. In this book, we are going to ignore the labels. For these situations, we think that the critical task for clinicians is to find a way to integrate complicated biomedical facts and realities with emotional, psychological, and social realities that are equally complex but not very well represented in the language of medicine. Working with life-threatening illness is a cross-cultural experience. As a clinician, you need to understand both the

biomedicine and the personal story, and you need to be able to speak in both languages.

In these situations, communication is not about delivering an information pill and seeing how much the patient can swallow; it is about sending messages to the patient and receiving messages in return. This back-and-forth model of communication has some important implications. First, paying attention to the process of communication is what will lead to a good outcome. So the preparatory steps we outline in the roadmaps may seem obvious to you – but to a patient who has never been in your clinic before, they can make a big difference. Second, communication is a two-way process. You have to think specifically about the messages you send and those you receive. If you are too busy sending messages to read the replies, chances are that the other person will stop bothering to send. And as a clinician, you may miss hearing important data.

Our basic principles

Throughout the book, we will illustrate a few basic principles, but we've collected them here to give you the big picture. These are more than pearls – they're the bedrock of our work.

1. Start with the patient's agenda. (This does not require that you ditch your own agenda; you just need to find out where the patient is.)
2. Track both the emotion and the cognitive data you get from the patient. (Don't look past the emotion.)
3. Stay with the patient and move the conversation forward one step at a time. (Never speak more than one step ahead of the patient.)
4. Articulate empathy explicitly. (You are creating a safe conversational space.)
5. Talk about what you **can** do before you talk about what you **can't** do. (You need to show you are working for the patient.)

6. Start with big-picture goals before talking about specific medical interventions. (Ensure that you have aligned your goals with the patient's goals before offering details about the interventions.)
7. Spend at least a moment giving the patient your complete, undivided attention. (When the patient tells you something big, put down your pen, stop typing on your computer and show him you are listening.)

A word about emotion

In this book, we emphasize a distinction between "cognitive" and "emotion" data. Since both of these words have a variety of uses, we would like to clarify what we mean when we use them in this book. By "cognitive" data, we are referring to conscious intellectual processes like thinking, reasoning, and judging. When you are talking to Mrs. E about prognosis and she mentions that she read on the Internet that the 5-year survival for her cancer was 50%, that is a piece of cognitive data. This particular piece of cognitive data tells us that she has consciously sought out information and tried to understand and comprehend it. Cognitive data tells us what patients understand rationally. On the other hand, when she flushes while she mentions this and you catch a look of distress flashing across her face, this is a piece of emotion data. Emotion is not under conscious control; it is involuntary. Mrs. E's flash of worry is a piece of emotion data tells us that this patient is having a tough time reporting to you what she has read because she is concerned about what it means for her. Emotion data tells us about a process of integration occurring in the parts of the brain that have to do with appraising value and creating meaning, because emotion processing prepares the brain and the rest of the body for action.

What does all this have to do with communication? In medical settings, we often hear physicians frustrated, irritated, or overwhelmed

with the emotion patients show, or we notice them trying to ignore emotion altogether. They dismiss emotion as human frailty and assume it has less value than cognition. In fact, emotion plays an important role: it determines how we decide what is valuable. And when you are talking to a patient with a life-threatening illness, figuring out what is truly valuable is often the most important underlying communication task. We consider emotion data to be as important as cognitive data and will emphasize recognizing and responding to emotions.

How to use this book?

You can use this book in two ways. You can flip straight to the chapter that addresses a challenge you currently face. Each chapter contains a step-by-step guide, or cognitive roadmap, that you can use to find your way through a difficult conversation. Alternatively, you can read the book straight through. Read in order, the chapters are designed to build a set of skills that will build a repertoire of communication tools that is powerful and flexible.

Maximizing your learning

During our retreats, we teach through interaction because the research shows that feedback is critical to put new communication skills into practice. On your own, there are other ways for you to learn the skills we teach at a course:

Record yourself. Listening to yourself or watching yourself is a humbling experience. (Does my voice really sound like *that*?) But it's worth the hassle. Don't forget to have your patient sign something that gives permission, but make it clear that you are doing this to become a better doctor. Even cynical patients will be impressed that you are trying to improve. Listen for what you say and what you sound like when

you're saying it. Better yet, have someone you trust watch or listen to the video or audio. Ask them to comment specifically on something you are working on.

Refine your observational skills. We have found that many physicians before communication training do not collect as much observational data – they are less skilled at recounting what happened. Lacking this observational data, they see communication as magical rather than a series of intentional observations, decisions, and words or gestures. So try to watch exactly what happens in your conversations. What did you say that worked? Or didn't work?

Practice one new skill at a time. Communication is a complex psychomotor skill, and until you've mastered one thing, it's hard to focus on something else. You wouldn't try to learn to use your new mobile phone while driving a new car, would you? Pick **one** skill. And the first time, pick something that doesn't look too hard. Remember that the best learning happens in situations that offer a bit of a challenge, yet aren't overwhelming.

Ask for feedback. Find someone else to watch you and give you feedback. Keep in mind that many medical professionals do not have highly developed feedback skills: they ignore your goals, don't notice your strengths, and tend to say something nice just before they say something mean. Therefore, don't open yourself up to a known character assassin. Give the person something specific to watch for. Tell them you really just want two or three observations relevant to a skill you are working on. Tell them you don't want their opinion about what you should have said – you want their observations (what happened?) about what you did say.

Do your own private debriefing. After a difficult conversation, find a couple of blank sheets of paper and, for a few minutes, write down everything you can remember about what happened. Include snippets of what you said and what the patient said, as well as reactions,

emotions, body language, and the effect of the conversation on you personally. Don't censor anything, just get it all down on paper. We try to put our pen on the paper and just keep writing for two or three pages. If other thoughts intrude, just write them down, then get back to the conversation. Later, see if a lesson or an insight emerges.

Be patient with yourself. Even though we are supposed to be experts, we still find ourselves chagrined because we lack patience, feel insufficiently spiritual, distract ourselves with petty ambitions, and remain perplexed about some things. Anne Lamott said wisely that "perfectionism is the enemy," so remember that you just need to stay on the path. Your mistakes can be portals to new learning. And remember, if you are trying to improve, you've already distinguished yourself from most physicians.

Pay attention when someone tells you that you did a good job. Working with life-threatening illness has a long learning curve, but it has its rewards. When you get positive feedback, pay attention. Don't brush off a compliment ("it was nothing," "it's my job"). Breathe deeply, take it in, enjoy the moment, and say "you're welcome."

You're ready to begin.

2 GETTING A GOOD START

Setting an agenda sets the stage

The first visit can make or break a relationship. In this chapter, we are going to talk about two principles key to developing a working relationship: asking first, and negotiating an agenda. These skills will help you start off on the right foot and build rapport with your patient.

A common problem

Several years ago, one of us (Tony) saw Jan D., a 50-year-old woman who had just had a breast biopsy showing cancer. Afterwards, she said that Dr. Back wasn't "in tune" with her from the beginning of the visit. "He seemed nice enough, but after a few minutes of questions about my allergies and family history, I interrupted and said 'Could we cut to the chase here?'" Tony was equally frustrated for a different reason. "It was one of those days when everything went wrong. But when she interrupted me, I realized I had blown it. She didn't think I was paying attention." What went wrong? They didn't agree on the agenda for the visit. Let's take a look at the encounter in detail.

WHAT HAPPENED	WHAT WE CAN LEARN
Jan D. is sitting in an examination room, waiting to meet her oncologist. There is just enough space for two chairs and an examining table. The magazines are old. Her appointment was scheduled for 20 minutes ago, and she hasn't received any explanation for the delay.	JanD. is anxious about her cancer, and this is her first opportunity to speak with a knowledgeable professional about it. She's already had to wait 2 weeks for this appointment, and she envisions the cancer cells growing every day. The appointment delay heightens her anxiety.
Dr. B is running late. His last patient, a young man with metastatic colon cancer that did not respond to first-line chemotherapy, was anxious and demanding. He didn't feel as though he really did enough, and he's still thinking about that encounter. Absentmindedly, he grabs the chart and walks into the room before he realizes he hasn't really looked through the referral information.	*The doctor is feeling harried and unfinished with his previous patient. He is not quite ready to tackle something new, and he has already made the error of starting unprepared.*
Dr. B: Hello, my name is Doctor Tony Back, please call me Tony. How are you today? Did you bring your records with you?	*The doctor asks two questions in a row, and the second question is a closed ended question. The second question negates the intention of the first.*
Ms. D: I gave the CD to the woman at the front desk yesterday.	The patient responds to the closed ended question, as one would have expected, and the pattern of the encounter is now set.
Dr. B: Were those your records or your scans?	*Another closed ended question … and sets the tone that he is focused on her medical information, not her.*
Ms. D: They told me it was everything.	
Dr. B: (looking through chart) Hmm, they didn't print it out for me. Well, maybe you can just fill me in on what's been going on.	*The doctor starts the visit without asking the patient about her agenda for the visit. And, there may even be some implicit blame directed at the patient for not bringing the "right" records.*
Ms. D: Ok, um … I'm really healthy, very active. Then my partner noticed this little lump in my right breast …	The patient emphasizes her underlying health.

WHAT HAPPENED	WHAT WE CAN LEARN
A couple of minutes later …	
Dr. B: Ok, that's the history. Now do you have any allergies?	*The doctor is going through the history and physical he learned in medical school. But, he has not acknowledged anything about her and how she must be feeling.*
Ms. D: (clears throat) Um, could we cut to the chase here? What are we going to do for the cancer?	The patient is concerned that her needs are not going to be met and voices her concern. This is also a sign of her anxiety bubbling through because the cancer has not yet been addressed.
Dr. B: Don't worry we'll get to that in a minute.	*The doctor dismisses the patient's concern without understanding it. At this point, major repair will be needed to gain Jan D.'s trust.*

Although Tony is doing a terrific job collecting the medical data, he is failing to connect with Jan D.'s concerns. The big problem is that he and Jan D. never negotiated the agenda for the visit, and so the visit defaulted to a discussion of the medical details (the doctor's agenda).

THE PROBLEM: Patient and doctor approach the visit with different agendas.

THE SOLUTION: Start the visit by negotiating the agenda.

The key principle

The conversation above would have gone differently if the doctor had used the first of the basic principles discussed in Chapter 1: *Start with the patient's agenda*. If Tony had started by first asking, "What do you

want to take away from our visit today?" he would have quickly learned how anxious Jan D. was and that she really wanted to know about treatment options.

We have met a number of physicians who don't like this question. They ask, "Won't it seem a little silly to say to someone who just found they had cancer 'What brings you here today?' Isn't it obvious that her cancer is the issue?" you may be surprised. She may be most concerned about treatment options, about the prognostic significance of the diagnosis, about whether the cancer is genetic. It could even be that the patient doesn't even believe she has cancer but her daughter made her come to the visit. Or it could be that the patient is so worried that she doesn't know what to talk about, and talking through what is going to happen in the next couple of steps would be a very comforting way to spend the visit. Understanding her concerns and fears is critical to how the rest of the interview goes. (You might not like the exact words we used here; if not, find some that work for you. It's the concept of agenda setting that we are promoting.)

The physician's goals

For the first visit, the physician's goals are to understand the patient's concerns, how she copes, and to establish some common goals. Tony could have avoided seeming "out of touch" by first asking about Jan D.'s concerns and then using that knowledge to build some common ground about what the visit should accomplish.

How to set an agenda for a visit (the cognitive roadmap):

1. *Make a welcoming statement.* Think of this as the beginning of the relationship – it should be inviting. If you are late, apologize. The apology need not be long, but an acknowledgment of your lateness

is important because it is common courtesy and it establishes your commitment.

2. *Ask about the patient's main concerns for the visit.* Because patients often have more than one concern, it is often helpful to say "anything else?" to ensure you have all the patient's concerns before you get into the meat of the interview.
3. *Explain your agenda for the visit.* Usually doctors have a number of things they want to make sure are covered. Make sure you have articulated these for the patient.
4. *Propose an agenda for the visit* that will meet that patient's concerns and your concerns. This agenda is the beginning of your shared goals for care.
5. *Ask the patient for feedback about the agenda*. Does your proposal seem like a reasonable plan to the patient? If not, the goals for the visit may need to be revisited.

Let's look at another encounter, after Tony learned to use this communication tool.

WHAT HAPPENED	WHAT WE CAN LEARN
Dr. B is running late again. But he takes a minute to flip through the chart and collect his thoughts so he can focus on his new patient.	*Even in the face of a bad and busy day, the doctor prepares. He does this because he knows that not doing so will only make that bad day worse and longer.*
Dr. B: Hi, Are you Mrs. Stevens? I'm Doctor Tony Back, you can call me Tony. I apologize for being late today, but I'm all yours now.	*Acknowledging lateness.*
Mrs. STEVENS: Hi, you can call me Ann.	
Dr. B: I got a note from your surgeon, Dr. H, that you were here to talk about breast cancer, yes?	*Volunteering information that shows continuity with the referring doctor.*

WHAT HAPPENED	WHAT WE CAN LEARN
Ms. A: nods.	
Dr. B: What are the big issues that you want to make sure I cover today?	*Asking explicitly about the patient's concerns.*
Ms. A: I want to know about the best treatment and the options for my stage of cancer.	
Dr. B: We will definitely cover that. Anything else?	*Setting the agenda with "anything else?"*
Ms. A: I'm also very concerned about my quality of life during treatment. Those are the main things for today.	
Dr. B: Great, because those are two of the things I wanted to cover also. Just so you know, I like to hear about your concerns at the beginning of our visits so I can be sure that we talk about them. In the future you can bring a list of questions if that works for you.	*Establishing the agenda by mentioning both the patient's and the doctor's concerns.Setting an expectation agenda setting in future visits.*
Ms. A: I'd appreciate that. Thank you.	
Dr. B: You're welcome. So, for today, here's what I propose. I'll spend a few minutes going over your history, to make sure I've got it straight. Then I'll do a brief exam. Then we'll use most of the time to go through those two big issues – the treatment options, and how this affects your quality of life. How does that sound to you?	*Making a proposal and asks for the patient's assent.*
Ms. A: Sounds fine.	

Asking about the patient's main concerns *before* launching into any discussion serves a couple of important functions in this encounter. Tony was able to set an agenda in just a minute with his patient. Second, it gave him an important window into the patient's concerns.

Establishing rapport

What exactly makes a relationship work? Rapport, as it occurs in clinical relationships, has three components: mutual attentiveness, positivity, and coordination. Mutual attentiveness is simply two people giving each other their undivided attention. Positivity is expressed in friendliness and caring; it doesn't mean that the physician has to be relentlessly upbeat, but rather that the physician seems interested in the patient. Coordination is the idea that the two people are "in sync," and this is what was missing from the first interaction. These concepts may seem abstract, but for some they may be more helpful than a list of behaviors which can make communication seem purely mechanical. The rest of this book will provide plenty of specific examples of behaviors for you to consider and try out.

As a relationship evolves, so too will the content of the visits. When patients see a doctor for the first time, they tend to be more focused on treatment options and logistics. They are getting a feel for whether they want to work with this doctor and, perhaps, this medical practice or health care system. In subsequent visits, patients are more likely to want to talk about quality of life issues and tough questions, such as "what's my prognosis?" Thus, what makes for good rapport changes over time. When a patient has enough trust to ask a question where a lot is at stake, and a physician can answer truthfully even knowing that the answer is not what the patient was hoping to hear, the relationship will become more powerful therapeutically.

Good rapport, and the communication that flows from it, requires attention to the process of the encounter. Physicians often think about communication as the news they need to give patients – they think of communication like delivering an information pill. You give the objective information to the patient, who has to swallow it. We use a different, more useful, model of medical communication. In this model, physicians, patients, and family members all send and receive messages of various

kinds. Or, at least, they try to send and receive messages. Communication failure – perhaps failure is too strong a word, so let's use breakdown – can be traced to the sender or the receiver. Therefore, two helpful questions for any communication breakdown are, "What was sent?" and "What was received?" Looking back at the first visit in this chapter, Tony intended to be complete and careful, but Jan D. thought he was being rigid and unresponsive. When Tony changed how he sent his initial message, the visit went much better. The overarching goal here is to develop goals and common language that both the patient and physician understand. The technique we have described here, agenda setting, can get you off to a solid start.

Communication breakdowns to watch for:

- A patient who has trouble participating in the agenda setting. The most common reason is a high level of anxiety. Or perhaps depression is making it difficult for the patient to focus on the topic. In these cases, the doctor can simply propose the agenda and explain the rationale. The doctor may not want to articulate the reason for simply delving into the visit, but may want to raise and address the reason before the end of the visit.
- The patient is accompanied by a family member or friend who has a different agenda than the patient. In this case, the doctor may need to elicit the family member's concerns and factor them into the agenda. ("Is it ok that I ask your wife what her goals are for today's visit? Mrs. Worth, what concerns do you have?")
- Some patients may wonder why the doctor is even asking. "After all," these patients say, "you are the expert, not me." The patient may be drawing on an assumption that the doctor will simply direct the entire encounter. But our question is, how would the patient want to be involved? In addition, our bias is that care for patients with life-threatening illnesses rarely works well when the patient is entirely passive. You may need to be explicit about the value of the patient's perspective. You might say, for example, "I think it is important for us to work together on your

health. It is helpful to me if I understand what is most important to you because then I can address your concerns and goals."

THE PATIENT WHO FIRED HIS LAST PHYSICIAN

I was seeing a new patient who had fired his last physician. Mr. White, a 62-year-old man with chronic obstructive pulmonary disease (COPD) and chronic back pain, had fired one of my colleagues, a physician for whom I had great respect – their relationship broke down over the patient's insistence on increasing doses of opioids and benzodiazepines. I decided that for several visits I would neither increase nor decrease his pain and anxiety medications, but focus instead on getting to know him. On the first visit, Mr. White talked to me mostly about how he needed more medication. The second visit was much the same. On the third visit, though, I decided to ask him how he spends his time every day. He told me that he just sat at home, a small one-bedroom apartment in an impoverished rural community. I asked him what he did when he sat – did he read, or watch TV? "No," he responded, "I just think." "What do you think about?" I asked. "I think about dying," he said. "And when you think about dying, what's that like for you?" "I think I'm going to hell," he said. And then, I said, "Tell me more," and the floodgates opened. He recounted his life story – how he had been imprisoned as a young man for stealing a car and had subsequently escaped from prison, only to be recaptured and given a harder sentence. Somehow, he managed to escape three times, at which point he was placed in maximum security for 20 years. As he put it, he "wasn't proud" of the things he had done in prison and was sure that he was condemned to hell for his transgressions. I did little more than listen to this amazing story. Over the next two years, he never again requested more opioids or anxiety medications. For Mr. White, my presence was a more effective analgesic and anxiolytic than any drug.

The bottom line

Spend a minute making sure you and your patient share the same agenda for the visit. Pay attention to the rapport you establish, because

in that first visit you are setting a pattern for the rest of your work with that patient.

Maximizing your learning:

1. Try setting an agenda at the beginning of the visit with just one patient during your next visit. Set yourself up for success by choosing a patient with whom you already have some rapport. Prepare some specific language: "Hi Mrs. Smith, I'm trying something new today. Before we move on with the business of the visit, I'd like to make sure I know all of the things you want to bring up, and then together we can set an agenda for the visit." Be prepared for the feeling that the words and what follows are unfamiliar – those feelings go along with learning a new skill.
2. After the visit, debrief yourself about what happened. Did you get the words out? How did Mrs. Smith respond? Did it have any effect on the rest of the visit?
3. Give yourself a reminder to try again. Try a sticky note, or a line on your to-do list. And, remember to debrief. You need repetition to incorporate and become confident about a new skill.

FURTHER READINGS

Coulehan, J.L. et al., "Let me see if i have this right …": words that help build empathy. *Ann Intern Med*, 2001, **135**(3): 221–7.

Epstein, R.M., Mindful practice. *JAMA*, 1999, **282**(9): 833–9.

Graugaard, P.K. et al., Changes in physician–patient communication from initial to return visits: a prospective study in a haematology outpatient clinic. *Patient Educ Couns*, 2005, **57**(1): 22–9.

Silverman, J., S.M. Kurtz, and J. Draper, *Skills for Communicating with Patients.* Radcliffe Medical Press, Oxford, 2005.

Suchman, A.L. et al., A model of empathic communication in the medical interview. *JAMA*, 1997, **277**(8): 678–82.

3 TALKING ABOUT SERIOUS NEWS

When the emotional channel is on high

A new diagnosis of a serious, potentially life-limiting illness is a turning point for patients and clinicians alike. For patients, a diagnosis signals entry into what one writer called "the country of illness" – a complex world involving loss, decisions, therapies, waiting, and work. For physicians, the capability to make these diagnoses and the responsibility that follows is powerful and, more recently, an unintended consequence of high-tech medicine. When diagnostic technology was limited, patients knew they had a serious illness only when symptoms became severe. Now, many diagnoses are made well before people experience any problems, and the medical literature contains a great deal of information, available to physicians and patients alike, about what a diagnosis means in terms of early death, complications, disability, and therapies that can modify the course of the illness. Physicians find themselves talking about life-limiting illness, diagnoses, and interventions earlier than ever before in the trajectory of illness. Thus, what the medical literature has called "breaking bad news" has become a fundamental task in the communication repertoire.

We would like to rename this task from "breaking bad news" to "talking about serious news." After years of teaching "how to break bad news," we have become concerned that framing the task this way tacitly encourages a view of this skill as information dumping. "Talking about serious news" frames the task more constructively for the physician and the patient. We're not backing away from the sadness or badness of having a serious illness, but we are orienting the physician to the task at hand. The goal of the physician faced with delivering serious news should be more about helping patients understand diagnoses and come to terms with their new reality than about forcing them to confront brokenness.

How the brain processes threats to life

When humans face danger, they respond in ways that are hard-wired into the brain, and these hard-wired responses occur much faster than rational cognitive thought. Danger triggers "flight or fight" responses – and cognitive processes get shifted into the background. When the primary threats to human life were out in the wild, these responses were highly adaptive: one's body was preparing to run for its life. In a physician's office, patients are likely to report hearing "nothing" after being told that their biopsy showed cancer. The automatic response to threat takes precedence over cognitive processing. Thus, for physicians giving serious news, the most important skill to acquire is the ability to detect and respond to patients' emotions. Only when this is done and the emotional storm passes will it be possible to discuss what should be done next.

Skating on the surface of the emotion data

In our experience, physicians tend to focus on the cognitive data, ignore the emotion data, and simply plow ahead. But this ignores what's

happening in front of them. Patients report a huge variety of reactions to bad news – everything from shock, surprise, anger, and acceptance. This variability makes it more important to figure out how the patient in front of you is reacting than to assume you know how "everyone" responds. Why do patients report so commonly that they "didn't hear anything" after the doctor gave the bad news? We think this happens because the patient's emotion – whether it is shock, anger, or something else – interferes with their ability to cognitively take in the news. Thus if you simply keep giving information when someone is in the grip of their own emotions, you are probably wasting your time. The conversation can *seem* pretty smooth, at first glance, especially if the patient reigns in or minimizes the emotion. But later, when it becomes apparent that the patient didn't understand much of what the physician said, the encounter breaks down. In the excerpt below, Mr. Clark, a man treated for non–Hodgkin's lymphoma a year earlier, is in the physician's office to learn the results of a computed tomography (CT) scan ordered in response to an lactate dehydrogenase (LDH) rise.

WHAT HAPPENED	WHAT WE CAN LEARN
Dr. B: Mr. Clark, how are you?	
Mr. C: Oh, I'm good, thanks.	
Dr. B: Ok, let's talk about what your lab tests and CT scan showed.	*Didn't check in to see what the patient is worried about.*
Mr. C: I'm ready, I guess.	
Dr. B: On your labs, the LDH has gone up a little bit more.	*Again not attending to the patient's distress and starting to give the news. Trying to forecast news that lymphoma has recurred with the news about the LDH. Ignored the hesitation perhaps covering worry in "I guess."*
Mr. C: Hmm, ok.	The patient does not seem to understand that the doctor is giving bad news.

WHAT HAPPENED	WHAT WE CAN LEARN
Dr. B: On the CT scan, there are some enlarged lymph nodes in the chest. And in the abdomen. It's a surprise –	*Using the "enlarged lymph nodes" to disclose cancer recurrence – doesn't use the word "cancer." And, is this a good surprise or a bad surprise?*
Mr. C: Yeah?	Again the patient does not seem to "get" that the news is serious.
Dr. B: – certainly not what we were expecting. I know you've been feeling so well.	
Mr. C: Could we back up a little?	
Dr. B. Sure.	
Mr. C: So, you say the lymph nodes are back? Does that mean the cancer is back?	Patient tries to clarify.
Dr. B: Yes.	
Mr. C: So, everything I went through, it's going to start all over again. Is that what you mean? I'm back at square one, basically?	The patient finally understands the news and predictably responds with emotion. This comment reflects distress about whether previous suffering from the cancer treatment was worthwhile. There is also some anger here.
Dr. B: In some respects, yes; in some respects, no. I would like to talk a little more about this, is that ok?	*Trying to keep things "rational" rather than "emotional."*
Mr. C: I don't know what to think right now. I just went through so much to get back to normal. And I've tried to be so much healthier, to take care of myself so much more. (pause) To know that it's back is hard for me to understand. I mean, is there any doubt?	Patient is still reacting to the news.
Dr. B: Well, I feel pretty confident that this is what it is. It's the return of the lymphoma. I know you had a tough time before, but I want you to know that this is still treatable.	*Responding to the cognitive issue without responding to the emotion. Trying to reassure the patient prematurely.*
Mr. C: And go where? Back to where I am now?	Patient doesn't sound reassured.

In this excerpt, the doctor has been completely accurate and truthful about the medical issues, and even respectful about when to move forward. Yet the patient's distress is palpable, and the doctor hasn't acknowledged the distress. The doctor tries instead to reassure, but doesn't know exactly what the patient is distressed about. The result is reassurance failure because the reassurance is premature – Mr. Clark doesn't think the doctor understands him. No wonder doctors can become cynical about their ability to help patients who are distraught. Given the nature of the news, there is no way Mr. Clark is going to leave the doctor's office feeling happy. However, if this physician had noticed and responded to the emotion data as well as the cognitive data, the patient might have left feeling cared for rather than feeling he had to struggle to understand.

Why tracking emotion is worth the trouble?

Earlier in this chapter, we mentioned that brains process emotion before cognition. This neurobiological finding produces the rationale for tracking patients' feelings – emotions can derail cognitive understanding. Thus, to complete a conversation with the patient ready to take the next step, be it another test, consultation, or whatever, it helps to take the emotional temperature of the encounter. It is data that will help you judge how much information to cover, how much understanding has occurred, and how fast you can proceed. How doctors talk about serious news is not just about being nice – it helps patients understand and adjust. In one study, patients who were dissatisfied with how they heard about their cancer were twice as likely to be depressed or anxious six months later.

THE PITFALL ABOUT GIVING SERIOUS NEWS: overlooking the emotional data.

THE SOLUTION: track the emotional data and respond to it.

Key skill: recognizing and responding to emotion

Dealing with emotion requires that you recognize it when it is displayed and respond. Think of emotions as a kind of clinical data, just as you think of how patients speak of their illness as data about their understanding of their medical situation. Learning to respond to emotions in an explicit way may seem silly – after all, aren't we all responding to people's emotions constantly? But the conscious use of emotional data is a skill that you will need to hone to optimize your ability to communicate.

This process is called empathy. Empathy means putting yourself in the other person's shoes and imagining what his life is like. To put it simply, empathy means "I am trying to imagine what it would be like to be you." Empathy is not just nice intention; real empathy shows up on functional MRI scans quite specifically as a specific kind of brain function. Responding to emotion, though, requires empathy and then action, you have to convey your understanding to that patient. Many physicians went into medicine because they wanted to utilize this capacity, but the process of training can leave us a little bit numbed, and even feeling that empathy can be a liability.

Understanding emotion data and how you can respond can help you cultivate empathic capacity, and in our experience, the sense of liability gives way over time to something much richer.

A simple framework for recognizing and responding to emotions looks like this:

1. Commit to observing and using emotional data in your communication.
2. Notice the patient's emotion, and name it for yourself.
3. Refrain from trying to fix or quiet the patient's emotion – this may require that you pay attention to your own worries and not act on them immediately.

4. Acknowledge the emotion explicitly. This can take many forms: nonverbal, such as eye contact, changing position, or perhaps touch (see box); expressions of understanding, support, respect, or exploration of what it is if you are uncertain but know something is going on. The acronym N-U-R-S-E summarizes how you can respond both nonverbally and verbally to emotions (see box).

RESPONDING TO EMOTIONS WITH WORDS

Patient's emotional statement: "These headaches are killing me!"

Empathetic physician's responses:

N	NAME the emotion:	"It sounds like this has been frustrating."
U	UNDERSTAND the emotion:	"It must be so hard to be in pain like that."
R	RESPECT (praise) the patient:	"I'm so impressed that you've been able to keep up with your treatment and the rest of your life while having these headaches."
S	SUPPORT the patient:	"I will be here, and my team, to help you with the headaches."
E	EXPLORE the emotion:	"Tell me more about how these headaches are affecting you."

Fischer, G., J. Tulsky, and R. Arnold, Communicating a poor prognosis. In: R. Portenoy and E. Bruera, eds., *Topics in Palliative Care*. Oxford University Press, New York, 2000.

The capacity of a physician to acknowledge and talk about emotions requires some care in choice of words. In general, you will do better to understate the patient's emotion and to show curiosity: not "you look furious" but "I'm wondering if you're concerned." The unskilled use of "emotion naming" can feel to patients as if you are labeling them. Many patients already have the impression that "good patients" don't emote too much – because it makes the staff uneasy.

Of course, we all respond to each other nonverbally – with facial expressions, hand gestures, body positions, and objects (think about glancing at a watch). While most of the communication research in medical encounters has focused on words, nonverbal communication is equally important and could be even more important. People tend to exert less conscious control over their nonverbal gestures, and thus nonverbals may be more telling – important to remember when you are facing a patient who is sitting stiffly with crossed arms and lips pressed into a thin line. However, nonverbal communication is also less specific and is easier to misinterpret.

The evidence about what you can do to improve your nonverbal communication is thin. There is one acronym, S-O-L-E-R, summarizing existing research, which stands for the following: (S) Face the patient *squarely* to indicate interest; (O) adopt an *open* body posture; (L) *lean* toward the patient; (E) use *eye* contact to show you are paying attention; and (R) maintain a *relaxed* body posture. While these are useful reminders, we would caution that nonverbal fluency requires more than leaning. The most powerful nonverbal communication we have seen comes naturally from a combination of technical expertise, commitment, and integrity – not a practiced gesture used now and then.

The cognitive map for talking about serious news

This map, developed by Rob Buckman and Walter Baile, has six steps originally named "SPIKES" (Setup, Perception, Invitation, Knowledge, Emotion, Summarize). Here we simply describe the steps because we want to emphasize the process of communication.

1. *Prepare for the conversation*. Have the information you need at hand. Find a reasonably quiet place in which you can all sit down. This affords the patient some privacy, and consequently safety that will enable him to ask important questions. Place a box of tissue in the room, which

can provide a bit of dignity if tears are shed (as the person won't have to wipe his face with his sleeve). If available, the presence of a nurse or social worker can allow the discussion to continue after you leave.

2. *Assess the patient's perception*. Asking what a patient understands or expects can provide an important window into the patient's perspective, especially if you are meeting the patient for the first time. If you ask, "What have other doctors told you so far?" and the patient replies, "No one has told me anything," you need to so some preparatory work before giving the news. The patient may in fact have been told very little, or more likely, the patient did not fully understand previous explanations. On the other hand, if the patient replies, "I have a 3 centimeter spiculated mass in my right lung," this indicates that the physician should be prepared to meet the patient with information at a more technical level. (When the doctor knows the patient well, this step may be unnecessary.)
3. *Ask for an invitation to talk about the news*. This step can seem superfluous – isn't it obvious that the patient is here to talk about the news? But think of this step as a way to allow the patient to shape how the serious news is discussed. Simply asking the patient, "Are you ready to talk about this?" gives him a bit of control and establishes that you want to work cooperatively. When you are working with patients where you suspect cultural mismatch, asking "how do you and your family want to deal with news that is serious?" can enable them to tell you how to avoid complicating the medical news with cultural insensitivity.
4. *Disclose the news straightforwardly*. First, consider a warning statement (we don't like the metaphor of "firing a warning shot"). This is a brief statement that allows patients to brace themselves for negative news. For example, "The biopsy came back, and there is some serious news that we need to discuss." You then need to provide the news in language that is immediately comprehensible to that particular patient. Beware of defaulting to medical terminology that will force patients to struggle to understand the news; the frustration that results

will increase the patient's distress. The more you can discuss the news using terms the patient understands, the more straightforward you will appear. Thus, being straightforward for a medically untrained person may not mean giving all the technical details right away – you may need to start with the bottom line, and fill in the details as needed later.

5. *Respond to the patient's emotion*. If you are tracking emotion data, you will likely notice a wave of emotion that follows the news, and this wave will probably not subside until long after the visit is over. The physician's job is to notice the emotion, give it some space, and recognize it as an influence in the discussion that follows. To be sure, acknowledging the emotion won't make it go away (see box). But responding to the patient's fear, anger, or numbness can provide a human dimension to a technical medical discussion and demonstrate how you care for the whole person.

   You should continue to respond to a patient's emotions until he has calmed down enough to hear cognitive information about what is next. A patient may tell you he is ready when he asks "Ok, what comes next?" Other times, you may have to check in by asking, "Is it ok if I move forward to talk about the plan and the options?" Watch the patient's response carefully. If he responds to this with more emotion, continue to respond empathically rather than moving forward with cognitive information.
6. *Summarize the plan*. At the end of the visit, be sure to summarize what you've discussed and describe concretely the next steps the patient will need to take. A brief written outline done during the visit can be extremely helpful to a patient and family later, and save your time in the future by reducing confusion.

Let's rewind back to Mr. Clark and see what happens when the doctor tracks the emotion more explicitly:

WHAT HAPPENED	WHAT WE CAN LEARN
Dr. B: How have you been doing since the CT scan?	*Assessing the patient's emotional state.*
Mr. C: To tell the truth, I've been kind of on edge.	
Dr. B: Like nervous?	*Clarifying and naming emotion data.*
Mr. C: Yes, I really couldn't sleep last night, I was thinking about everything.	
Dr. B: Well, waiting for results can be nerve-wracking, I know.	*Acknowledging the patient's worry.*
Mr. C: (nods).	
Dr. B: So let's talk about the CT scan, ok?	*Asking for an invitation.*
Mr. C: Of course.	
Dr. B: The CT scan showed something serious. The cancer has come back in the liver. There are five new spots of cancer.	*Using a warning, then disclosing straightforwardly.*
Mr. C: Oh, my god.	
Dr. B: (takes deep breath, waits).	*Using silence to give the patient time to respond. Silence works when the doctor provide an "empathic space" by sitting near the patient, possibly putting his hand on the patient's shoulder, and keeping the focus on the patient – not writing or typing.*
Mr. C: How can this happen?	Emotion: shock.
Dr. B: It's a shock to me, too. I was hoping not to see cancer.	*Naming own emotion, echoes patient hopes.*
Mr. C: But I've been so healthy. I gave up red meat. I did all that chemo before. That was supposed to help. Should I have gotten more?	Patient still shocked, searching for explanation, starting to move into disappointment.

WHAT HAPPENED	WHAT WE CAN LEARN
Dr. B: I think you did everything right, everything possible to prevent this. I'm very disappointed too.	*Naming disappointment, and praising the patient for his efforts in fighting the cancer.*
Mr. C: How will I tell my kids?	
Dr. B: We'll work with you on that. It's hard to talk to your kids and it's very important.	*Responding to worry by offering support to help the patient manage this challenge, and underscoring importance of patient's concern.*
Mr. C: Ok, what about the treatment?	
Dr. B: Let's talk about the plan. I will work with you all through this, I want you to know. How about if we start with the treatment options?	*Responding to the patient's question showing readiness; giving a roadmap for the rest of the conversation, asking whether patient is ready to proceed.*

The emotional subtext in this conversation is much more evident than in the previous one. The patient's concerns are more obvious, more in your face, more raw. His distress is right on the surface and, at first blush, this conversation looks like it would be more difficult. Yet, the reality is that, for a physician who can deal with the emotions, this conversation is actually easier because you know more about the patient's reaction. When you know what the concerns are, you can address them more directly. The result is less time spent on issues you assume will be worrisome that actually are not, and more time spent on the issues that count.

Why don't physicians pay more attention to emotion?

There are a variety of theories about this but we think that most physicians just haven't learned how to deal with emotion in the context of

a medical visit. We hear physicians say that they feel pressed by time, worry about opening "pandora's box," and feel uncomfortable with strong emotions.

The core of empathy is the ability to observe another person's emotional state. Neurobiologists have discovered "mirror" neurons that enable us to place ourselves metaphorically into the shoes of another person. For a clinician, the skill is to use that mirroring capacity and not become completely absorbed in it. Thus, one must possess the capacity to "create a place to hold the patient," from which one can shuttle back and forth – feeling their emotion and your emotion. Without this skill, the emotion can seem like way too much to deal with. How do you get there? You must build your awareness of your own emotions and your ability to tolerate your own strong emotions. This will allow you to be present and even therapeutic in the presence of the strong emotions of your patients.

What if the family says "don't tell"?

One special situation worth discussing is when a family member asks you not to tell the patient about their diagnosis. Nondisclosure raises ethical questions about which all parties have strong conflicting opinions. In such cases, if patients are told their diagnosis, then families feel ignored and disrespected. Yet, not telling a patient may violate his autonomy and your conscience. The conflict can often be avoided by using the previously discussed skills of asking before telling and attending to emotions empathically.

Start by attempting to understand the family's point of view. Remember: in virtually all cases, the family has the best interests of the patient at heart. "Tell me about your concerns" is a much better way to start than "We have to tell her," and will help show the family that you are interested in their story. You may find out that the

patient had clearly stated that he or she did not want to be informed of bad news and preferred to defer to family members. In other cases, families assume patients' views based on how similar situations were handled in the past. Where family members presume patient agreement with nondisclosure, the clinician may suggest the possibility that the patient might have a different opinion. "I wonder how we would know if your mother did want to know more about her illness?"

In most cases, however, families base their desire to "protect their loved one" from bad news on a belief that the news will cause unnecessary suffering. They want to protect their loved one from feeling the distress that they are feeling. It is therefore important to respond empathically to families' emotions. An example of such a response might be, "I understand this must be a difficult time for you and your family." Or "I see how worried you are." (Interestingly, these behaviors may help the family feel more confident that you will talk to their loved one in a sensitive way.) In discussing the family's view, it is important to respectfully talk about the implications of not telling the patient the diagnosis, "I wonder if you have thought about some of the practical issues associated with not telling your mother about her diagnosis. Can I mention some of my concerns?" For example, if a request is made to inform a patient with cancer that he or she has an infection, families generally have not considered how to explain the necessity of treatment in a clinic with a sign that includes the word "cancer."

In our view, the challenge is to figure out what the patient wants to know, without actually disclosing the news in the process. The simplest way to do this is by asking patients directly how much information they want to hear. In discussing this with the family, it is important to be explicit that the goal is *not* to talk the patient into doing this one way or the other.

"I'm fine with you (the family member) being the decision maker, if that is what she wants. I just want to confirm that, so we are doing what she wants."

As a part of this negotiation, certain ground-rules and possible outcomes should be considered in advance. First, role play with the family about exactly what you are going to say to reassure them that you are trying to be respectful to the patient's wishes. We tell the family that we are going to say to the patient "Some patients want to be told directly about their illnesses and others would prefer for the family (or a specific individual) to be in charge. What do you want in this regard?" Second, you should discuss with the family who will share information with the patient if it turns out the patient does want all the information. Finally, you should discuss if the family wants to be present for this conversation with the patient or whether they want you to do it alone.

If the news is a medical error

Admittedly, medical errors are not the main focus of this book but it is worth mentioning the importance of disclosure by the physician responsible for the patient's care. The roadmap is very similar to what we've described earlier. Treat the error as serious news, and add an apology. When patients find out about errors in a roundabout way, and don't receive direct explanation, they lose trust in the physician. The apology is repair, and you need to offer it without expecting that it will make good the problems caused by the error. The possibility of maintaining some trust lies in your willingness to come clean and offer the apology. What most physicians will need to deal with before they offer the apology, however, is their own guilt, and this is part of the preparation for this particular brand of serious news.

LISTENING BETWEEN THE LINES

I was seeing an Asian woman with metastatic pancreatic cancer. The primary team asked me to talk to her about her diagnosis and its implications. I went in to talk about the CT done the previous day and "give her the bad news." But before I even gave her the news, the patient volunteered that she had been caring for her daughter's father-in-law. She was incredulous that the "doctors had told him his diagnosis" – of cancer. When I asked what she meant, she said, "Doctors should never tell patients that they have cancer, they should talk to their family. It is too much of a burden to tell a patient." She was telling me that she did not want to know her own diagnosis. And she reminded me how important it is to ask "how much information do you want to know?" before giving serious news.

The bottom line

When giving serious news, track the patient's emotion data: it can be more important than the cognitive data.

Maximizing your learning:

1. Give yourself a few minutes to think back to a memorable incident in which you were giving serious news. One way to do this is to write in a journal the first things that come to mind. Don't worry about grammar, penmanship, or coherence. Don't judge anything as good or bad, just pay attention to what comes to mind. Sometimes even writing is too exclusively left brain, so if you feel constrained by writing, just sit back (in a quiet place) and open your mind to images, feelings, sensations. Just collect them and see what comes up. How have these stories or images or feelings influenced how you approach giving bad news?
2. Choose one new skill from this chapter to work on – just one! We want you to focus your learning energy. For example, if you want

to practice making empathic comments, choose a starting place (e.g., "I'm going to acknowledge sadness when it comes up"). Then commit yourself to trying it in clinic – tomorrow or next week. Make yourself a reminder, and a time to debrief yourself (this could be as simple as the time on your drive home).

FURTHER READINGS

Baile, W. F. et al., SPIKES – a six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist*, 2000, **5**(4): 302–11.

Barclay, J. S., L. J. Blackhall, and J. A. Tulsky, Communication strategies and cultural issues in the delivery of bad news. *J Palliat Med*, 2007, **10**(4): 958–77.

Delbanco, T. and S. K. Bell, Guilty, afraid, and alone – struggling with medical error. *N Engl J Med*, 2007, **357**(17): 1682–3.

Eggly, S. et al., Discussing bad news in the outpatient oncology clinic: rethinking current communication guidelines. *J Clin Oncol*, 2006, **24**(4): 716–9.

Friedrichsen, M. J., P. M. Strang, and M. E. Carlsson, Breaking bad news in the transition from curative to palliative cancer care – patient's view of the doctor giving the information. *Support Care Cancer*, 2000, **8**(6): 472–8.

Parker, P. A. et al., Breaking bad news about cancer: patients' preferences for communication. *J Clin Oncol*, 2001, **19**(7): 2049–56.

Ptacek, J. T. et al., Breaking bad news to patients: physicians' perceptions of the process. *Support Care Cancer*, 1999, **7**(3): 113–20.

4 DISCUSSING EVIDENCE FOR MAKING TREATMENT DECISIONS

"How would you like to be involved in this decision?"

After delivering serious medical news, the next communication task is often to address treatment options. In discussing decision making, a physician must summarize a body of biomedical evidence, present choices to the patient, understand the patient's perspective, and finally come to a decision about which option to pursue. This multifaceted process is complex and, in its totality, goes beyond the scope of this book. Yet one thing is clear: discussing treatment options is much more than simply giving information. Many recommendations about discussing treatments seem to assume that physicians dispense information like a drug, and that more is always better. While information is important, and patients do wish to be informed, offering more information alone is too simplistic a guide for physicians helping patients with difficult decisions.

In this chapter, we discuss how to communicate evidence that should bear on the treatment decision, and how to talk about, or frame, the decision-making process. Our approach is based on studies that have examined how patients feel about information, how they absorb information, and how they want to make medical decisions.

Although we do not intend here to present a comprehensive treatment of decision making, we do offer several clear communication tools that, we hope, will make the decision-making process easier for you and your patients.

Information as a double-edged sword

Sound decision making rests on patient and physician use of medical information, and a variety of studies suggest that many patients with life-threatening illnesses believe they have not received enough information. The majority of patients report that they want as much information as possible, although a significant minority (10%–20%) indicates that they have reservations about hearing bad news or do not want to hear all the details. Information can help patients make good medical decisions, promote compliance, create realistic expectations, reduce anxiety, and promote self-care.

Because providing information has these beneficial effects, U.S. physicians have, over the past 60 years, moved strikingly toward explicit disclosure about life-limiting illness. For example, in 1961, 90% of physicians surveyed said that they would prefer not to tell a patient with cancer his diagnosis; in 1979, 97% preferred to tell the patient they had cancer. That is a sea change in behavior over less than 20 years! With the rise of treatment options and biomedical complexity, medical ethicists have championed patient autonomy and self-determination as a "right." Yet studies also show that in the setting of life-limiting illness, information can be scary, and depressing, and many patients find information to be a double-edged sword.

The Internet has changed how patients obtain information. Many patients come to visits having read a great deal online. Yet studies indicate that patients still turn to their doctors as the most important and trusted source. One study found that patients went online to check

recommendations and information they received from their physician, and that patients wanted to develop expertise about their own condition. Physicians today need to take patient information-seeking into account when discussing treatment options, and realize they are working in partnership with the Internet.

Steering between informing patients and overwhelming them

What's the problem with providing lots of information to patients with serious illness? Information about potential treatments and options is loaded with emotional overtones, not because the information itself is loaded, but because the implications of treatment success and failure may be life or death. Information overload occurs when heightened emotions on the part of the patient surrounding a discussion of treatment options leave the patient unable to absorb the amount of information that the patient could otherwise manage in a less stressful moment. Physicians who no longer find the survival statistics surprising, and whose own lives are not at stake, tend to underestimate the effect of stress and assume the patient is taking everything in. In one of our own studies, a patient put it this way: "After he said the 30% [overall survival] he just kept dinging along in his facts, and I was stunned. Literally, my note-taking was completely done. All I wrote was '30%' the rest of the time all over my paper. And I mean, I just couldn't get past that point. I don't know how to describe it."

Involving patients in decision making

In addition to the question of how much information to share, patients vary widely in how much they want to be involved directly in decision making. Degner introduced a useful conceptual model that places

patients on a spectrum between a paternalistic or physician-centered decision, to a consumerist or patient-centered decision. Existing studies, and there are relatively few, suggest that a substantial number of patients are not able to participate in the way they would have liked. Although there is some debate about whether patient-centered or physician-centered is better, we think the real issue is how to figure out what the patient needs.

The roadmap for involving patients in medical decision making:

1. *Prepare for the visit*. In Chapter 3, we mentioned the importance of having an appropriate place and time, and the same is true here. In addition, the physician has to know the relevant evidence about potential treatments and how it applies to this particular patient. Thinking out loud while sitting in front of the patient is unlikely to improve the patient's comprehension, and worse, can give the impression that the physician is indifferent, unengaged or, at worst, incompetent.
2. *Frame the decision to be made*. It is important to clearly describe the decision faced by the patient. For example, "The issue we need to decide is whether you should have surgery for your aortic stenosis." As part of this framing, the physician may find it necessary to summarize the medical history or recapitulate key findings, and to elicit the patient's expectations and understanding. Ask permission to talk about the decision today. "Is it ok if we talk about what should be done today? Is there anyone else you want to be here when we make this decision?"
3. *Ask about decision-making preferences explicitly*. "When you have to make a significant medical decision, how do you want to go about it? Would you rather hear the pros and cons and decide yourself, or

decide together with me, or would you rather have me decide what's best for you?"

4. *For patients who want shared decision making or patient-led decision making, outline the options*. Explain that there is a lot of information and encourage the patient to stop you if they become confused. Review the pros and cons of each option in turn. Clarify that the patient has understood and ask for patient feedback. Offer to make a recommendation.
5. *For patients who prefer physician-led decision making, make a recommendation*. Explain your rationale for the recommendation, and discuss why you think this option is better for the patient than the other available options. Ask for patient feedback and questions.
6. *Check for patient understanding*. A simple way to accomplish this is to ask, "Tell me what you are taking away from this discussion." Alternatively, you can put the responsibility on yourself and say, "Sometimes I don't do a great job explaining everything. To help me make sure I was clear, could you tell me in your own words what you understand about the treatment options?" Questions that can be answered with "yes" or "no" (such as "Are you following me?") are somewhat less useful because patients may simply answer yes out of politeness.
7. *Establish how the patient wants to proceed with the decision-making process*. "Sometimes people are ready to make a decision, and sometimes they want to think about it for a while, perhaps talk to other people. What would be best for you today?"

In the following excerpt, we've picked up a conversation midway into the visit. Dr. B has been reviewing scans and is ready to turn to a discussion about palliative chemotherapy for metastatic colon cancer. Dr. B has already prepared by checking to see if any clinical trials

are available, and reminded himself about the statistics for treatment response with a quick Internet search because he remembered Mr. A as being very interested in discussing details.

WHAT HAPPENED	WHAT WE CAN LEARN
Dr. B: So is it ok if we go on now to talk about treatments for the colon cancer?	*Asking permission to proceed is a nice way of giving the patient an idea of what's next while giving him an opportunity to ask questions.*
Mr. A: Yes, I'm ready.	
Dr. B: I have a couple of very good options for treatment, and I think the next step is picking the option that is best for you.	*Framing the decision to be made.*
Mr. A: I want whatever would be best. And I want to get started as soon as possible.	
Dr. B: I want to give you the best, and in this case it turns out that there are different kinds of "best" depending on what's important to you. I also want to make sure you are involved in choosing the way you want. Are you the kind of person who would want to be the decision-maker yourself? Or would you want me to decide for you? Or are you more in-between – we decide together? How should we do this?	*Joining with the patient in wanting the "best." Note that Dr. B doesn't explore this now, as he can ask more as he explains the options. Asking explicitly about decision-making preferences.*
Mr. A: I should want your input, certainly. I want your experience on this.	
Dr. B: I'll make sure to talk about my experience with the options then. Can I lay out the options? I'll write them down as we are talking on this piece of paper.	Dr. B writes an outline of the options that leaves the patient with a written record of the conversation.

WHAT HAPPENED	WHAT WE CAN LEARN
Mr. A: Thank you, that will help me remember.	
Dr. B: For your disease, our main choice of treatment is chemotherapy. I want to talk about the two best options for chemo for you. Option 1 is … Option 2 is … Now I'm going to talk about the pros and cons of each option. Stop me if I'm not clear about something … Now what questions do you have?	*Describing options explicitly.* *Giving permission to be interrupted.* *Asking for questions.*
Later …	
Dr. B: I want to make sure I've explained these options well enough and that you are clear about the differences. Would you mind telling me in your own words about the different choices and how you feel they might affect your life?	*Checking for understanding using open-ended methods.*
Later …	
Dr. B: Do you feel ready to make a decision now, or do you want to go home and think and have another appointment?	*Establishing decision-making process.*

While we wanted to illustrate how to lay out the decision in the conversation above, the doctor didn't quite get around to using the statistics, and this is a sticking point for many physicians. We find that statistics illuminate and confuse in nearly equal proportions. We can, however, endorse two practices. The first practice is to pick the one or two most important statistics to discuss (and there is more about this in the next chapter), and focus on those. The second practice is to double-frame the statistic – that is, talk about the percentage that will be cured and also the percentage that will relapse. There is some evidence that double-framing helps patients understand better.

Decision-making aids that really work

The decision-making literature describes many written, computer-assisted, and coach-based self-management aids for patients' decision making, but they have limited availability and fall outside the focus of our book. We would, however, like to suggest two simple aids that clinicians can use to immediately enhance the quality of their communication. The first is a brief written summary. Described by Tom Smith, the brief written summary is a handwritten single page that the physician fills out while talking to the patient and that provides a very basic outline of the conversation. We find this to be tremendously helpful in improving patient comprehension. The outline includes the diagnosis, stage (this was designed for cancer), treatment options, outcomes, and side effects. While this is based on the cancer literature, you could modify this outline for most medical decisions.

The second aid is giving patients an audio-recording of the patient–doctor visit. There have been a variety of randomized trials examining the use of audio-recordings, and the effects are generally positive. This technique takes almost no additional time, only that of asking the patient and turning on the audio recorder. Although the recording does help patient comprehension and is found to be particularly helpful for family members who were unable to attend the clinic visit, not all patients will appreciate listening to these difficult conversations again. When discussing recurrent cancer, the outcomes of giving patients recordings are mixed, because patients find that listening to the audiotape causes more distress.

What about visual aids? Besides the fact that there is limited data to show what format is better for what kind of patient (pie chart versus 100 dots?), we just wish these were more available because we don't have time in clinic to make them.

The bottom line

Ask patients how they want to make decisions – it's an investment that will pay off in efficiency and satisfaction.

Maximizing your learning:

1. Choose one skill to work on. As before, commit to practice. For example, start asking patients about their decision-making preferences. Ask yourself the following question: How will I know if I'm doing better? For example, you might leave the visit with a clear view of the patient's preferences about making decisions. You might even ask the patient at the end of the visit how they felt about your asking them about their preferences.

FURTHER READINGS

Ariely, D., *Predictably Irrational: The Hidden Forces that Shape Our Decisions. HarperCollins*, New York, 2008.

Epstein, R. M., B. S. Alper, and T. E. Quill, Communicating evidence for participatory decision making. *JAMA*, 2004, **291**(19): 2359–66.

Groopman, J., *How Doctors Think*. Mariner Books, Boston, 2008.

Harrington, S. E. and T. J. Smith, The role of chemotherapy at the end of life: "when is enough, enough?" *JAMA*, 2008, **299**(22): 2667–78.

Lidz, C. W. et al., Barriers to informed consent. *Ann Intern Med*, 1983, **99**(4): 539–43.

Smith, T. J., Tell it like it is. *J Clin Oncol*, 2000, **18**(19): 3441–5.

Sox, H., M. A. Blatt, M. C. Higgins, and K. I. Marton, *Medical Decision Making*. American College of Physicians, Philadelphia, 2006.

5 DISCUSSING PROGNOSIS

Damned if you do, damned if you don't

When discussing prognosis, physicians face a series of contradictory impulses. For many, telling patients that their illness will take their life makes doctors feel like they are giving out a "death sentence." The prognosis conversation is difficult, and often times it's easier to let these issues slip into the background and focus instead on symptoms, logistics, or hoping the patient will respond to treatment. Yet, these same physicians also know that when patients don't realize how close to death they really are, they often fail to make plans, including sharing preferences for the medical care they want at the end of life. When this occurs, families and clinicians are left making decisions for them – often with conflict and heartache. Thus, for many physicians, the impulse to inform the patient and the impulse to avoid a discouraging discussion coexist.

Patients have their own contradictory impulses. On one hand, in surveys, patients consistently say that they want a great deal of prognostic information. For example, in one British study, 87% of patients wanted "all possible information." On the other hand, patients also warn clinicians about being "too blunt," and say that "supporting hope"

is very important. To further complicate matters, a significant minority of patients wants to avoid prognostic information altogether, and in some cultures, to speak about a bad prognosis creates a self-fulfilling prophecy. How can a doctor possibly get this right?

Finally, both patients and physicians must deal with the limitations of using statistical data. A statistic addresses the average outcome for a population, which is not the same as predicting what will happen to an individual person who may be the outlier on the survival curve. Many patients, who hear the data and fully understand the implications of a 5% 5-year survival, are also fully convinced that they will be one of those lucky 5%. Physicians share this optimistic bias. A study that asked physicians to predict survival for their patients being referred to hospice found that they offered more optimistic prognoses the longer they had known the patient. Why? Perhaps because it is difficult for physicians to foretell deaths for patients about whom they care.

THE PITFALL: Assuming you know what the patient wants re: prognosis.

THE ANSWER: Ask patients how they want to talk about prognosis.

Realists, optimists, and avoiders

Given these conflicting motivations, it's no surprise that physician behavior is quite variable. Doctors' strategies place them into three general groups which we call the "realists," "optimists," and "avoiders." These strategies correlate with research that shows 37% of physicians would tell a patient a prognosis they thought was accurate, 40% would be partially accurate (and usually optimistic), and 23% would decline to discuss prognosis altogether, even if asked directly. Each strategy is based on some principle – and also comes with unintended

consequences. Realists emphasize that they are supporting patient autonomy; patients need to understand accurately to make good decisions. The unintended consequence is that realists can come off as blunt and even brutal. Optimists emphasize that they support patient hopes; patients look to physicians for encouragement and a sense of what's possible. The unintended consequence is that optimists sometimes leave patients and their families unprepared for death. Finally, avoiders emphasize the limits of statistical information and the inability to predict an individual disease course; patients don't benefit by receiving inconclusive data. The unintended consequence is that avoiders can seem cold, evasive, and unwilling to share their expertise and experience, thus losing patients' confidence.

Physicians and patients influence each other in how much discussion of prognosis occurs. One extreme version of this mutual influence was depicted in a study that showed physicians and patients tacitly agreeing to a "don't ask, don't tell" arrangement or collusion not to discuss the uncomfortable facts about disease. The patients generally learned about their own prognosis by talking to other patients in the waiting room who were further along in the illness or discerned it from their own bodily decline.

Negotiating what to talk about

Because many patients want some prognostic information and because there are many types of prognosis to talk about (disease-free survival, overall survival, response to a treatment, likelihood of surviving a year), it's difficult, if not impossible, to predict what a particular patient wants to know. Whereas we know that education correlates with a desire for more information and more advanced illness correlates with wanting less information, such general trends are not useful when faced with an individual patient. A clinician can only give the "right" amount of information

after understanding what the patient wants to know, and patients report that they want to negotiate when to talk about certain topics. So, we have developed a negotiation-based strategy for dealing with prognosis.

The opening question: how much do you want to know?

We find that patients can generally tell us what they want to talk about and what level of detail they want. Thus, we start with a simple opening question: "How much do you want to know about prognosis?" This question has a couple of functions. It invites a response that goes beyond "yes" or "no," and it establishes prognosis as a topic where a certain amount of give and take between clinician and patient is possible. The physician may choose to normalize a range of patient interest by saying, "Some people want lots of details, some want to focus on the big picture, and some would rather not discuss what may happen in the future altogether. What would be best for you?" How the patient responds enables the clinician to take the next step. Patients give three kinds of responses: they want to have an explicit discussion with information; they don't want the information; or they are ambivalent, meaning that they want it and don't want it simultaneously.

For patients who want information

The principle underlying this kind of discussion is that patients are more likely to try to understand and retain information they want.

1. *Negotiate the content of the discussion.* Physicians can negotiate information giving by establishing a patient's information needs and proposing ways to meet those needs. These negotiations enable patients to indicate their interest and readiness to hear specific types of information. For example, in response to a patient who

said, "I want to know my prognosis," a physician might say, "What kind of information do you want about the future?" If the patient seems stuck, the physician could say, "There are several ways I can answer your question, so tell me which would be best for you. One way I can answer is to give you some statistics – the average time a person with this disease at this stage lives. Or, I can talk about the worst case scenario and the best case scenario? Or sometimes people are thinking about a specific event in the future, like they are hoping to live until their anniversary. Which one of these would be the most helpful?"

2. *Provide the information*. At this point, the physician will know that the patient is interested in hearing prognostic information and is clear about the type of information the patient wants. With the context of the discussion set, a physician can deliver information – even difficult information about poor prognoses – straightforwardly. If a patient has said, "I want to hear the average length of time that a person with this disease lives," then the physician can answer, "The studies for patients with metastatic colon cancer show that half of the patients have died by 2½ years, and about 95% have died by 5 years." One sentence, such as this, is enough before you should stop, pause, and check in. Give factual information slowly, in small, bite-sized chunks, to allow the patient time to digest and react to the data before you continue.
3. *Acknowledge the patient's and family's reaction to the news explicitly*. The patient and family are likely to have some kind of emotional reaction to prognostic information, particularly if it is bad news. We commonly observe physicians withdraw from these emotional reactions, although our experience is that a physician's verbal acknowledgment of the reaction can facilitate a deepening of the conversation. For example, you may say "It looks like that information was not what you were expecting," or "What is your reaction to

this?" or "I can see this is a bit upsetting." For this step, we recommend empathic statements that demonstrate explicitly that the physician perceives the emotion, understands the patient's situation, respects the emotion, supports the patient, or wishes to explore the reaction. (See "Responding to emotions with words" in Chapter 3 for a list of different empathic statements that are often helpful.) While an empathic silence can be extremely powerful, in this particular situation, silence can also leave patients unsure whether they can talk to their physician about their emotional reactions.

4. *Check for understanding*. Patients and family members often misinterpret complex medical information, hearing only the bad or good aspects of the message. Thus, physicians should check whether the patient heard the message the physician intended to convey. For example, a physician might ask "Tell me what you are taking away from this discussion?" or "Tell me what you will tell your spouse (or friend) about our conversation?"

A sample conversation with a patient interested in information and its follow-up is shown here.

WHAT HAPPENED	WHAT WE CAN LEARN
Dr. T: We've been talking a lot about where you are with your illness. Would you like me to talk about the prognosis for this kind of cancer? What kind of information do you want me to cover?	*Asking the opening question.*
Mr. K: I need to know how long I'm likely to live. I have plans.	He is a patient who wants explicit information.
Dr. T: If you don't mind telling me a bit about your plans, I might be able to give you information that is more useful.	*Negotiating the content of the discussion.*

WHAT HAPPENED	WHAT WE CAN LEARN
Mr. K: We have a trip planned with my oldest friend and his wife in the fall, and my granddaughter is graduating in the spring.	This is his personal context for the information.
Dr. T: Ok, that's helpful. So I think it is very likely you will be able to go on your trip, since that is coming up in a few months. I even think that you have a reasonable chance of making your granddaughter's graduation in a few more months.	*Providing information in the context of the patient's personal timetable.*
Mr. K: (silent)	*It is useful to try to imagine, "what is he thinking?"*
Dr. T: Is that what you were expecting?	*Acknowledging the patient's reaction by empathic exploration.*
Mr. K: I'm just relieved, I guess.	
Dr. T: I know that talking about prognosis can be … well, touchy.	*Making another empathic response.*
Mr. K: You're right.	
Dr. T: Do you want to discuss more today?	
Mr. K: Not really. But I might another time.	*This was important. Knowing that the patient wanted information, the doctor might have been tempted to share more specific survival data. However, as he learns here, that would not have been welcome. He has already met the patient's need.*
Dr. T: So tell me what you're going to tell your wife about this conversation.	*Checking for understanding.*
Mr. K: That you said I would probably make it to our granddaughter's graduation.	The patient has understood accurately.
Dr. T: And we can discuss more next time. Do you think she might want to be here for that?	

These conversations unfold over time, so the following encounter picks up at a subsequent visit.

Mr. K: I've been thinking – we talked about my granddaughter's graduation, but really what kind of time are you talking about? Is it years or what?	**Now, after processing some of the information, he appears to want more detailed statistics.**
Dr. T: So would you like me to talk about how long patients with stage 4 colon cancer typically live?	*Negotiating the content of the discussion.*
Mr. K: Well, I suppose so. But can anyone really say?	
Dr. T: I don't know how long an individual person will live. What I can do is tell you the average for a group of people with this kind of cancer.	*Setting up the ensuing discussion for patient to appreciate the difference between population and individual estimates.*
Mr. K: Ok. I'm a planner so I want to know the facts.	He sounds very clear about the benefits for him.
Dr. T: So even though I'm not really able to predict exactly how long you will live, here's what I can say: Most people with metastatic colon cancer with cancer in the liver who are getting anticancer treatment live for months to years. What I mean by this is that in a bad case scenario, people live a few months, and in the best case scenario they can live a few years. If you look at the average for all patients with this kind of cancer, it's about two years. Because you are otherwise pretty healthy and have responded well so far to all the treatments, I am hopeful you will do better than most. Does that make sense to you?	*Providing the information.*
Mr. K: Yes. Well, I guess that's kind of a relief.	Hmm. I'm not sure what his reaction means, so I'll check.

Dr. T: What do you mean?	*Acknowledging the patient's reaction by empathic exploration.*
Mr. K: I thought it was going to be worse than that. I had a friend who had this and only lived a few months. Although 2 years isn't that good, is it?	
Dr. T: I wish it were longer. This is just an average figure, though, not a prediction for you personally. I'm hoping you will do better. You are healthier than a lot of patients I see with cancer and that is a good sign.	*Acknowledging the patient's reaction.*
Mr. K: Thank you for being so clear.	
Dr. T: You're welcome. Could you tell me what you're taking away from our conversation today?	*Checking patient understanding.*
Mr. K: That I'm healthier than some other people with this cancer and maybe I can do better than the average, which is about 2 years.	
Dr. T: I think you've got a very good understanding of the situation. Now let's move on …	

For patients who don't want information

Some patients will indicate in response to the opening question that they do not want to discuss prognostic information, leaving the physician in an awkward place: on one hand, wanting to respect the patient's wishes, yet on the other hand, worried that hopes rather than facts may cloud patient decision making. Three general principles are useful in these situations: first, understanding why a patient doesn't want to know may – paradoxically – enable a physician find a way to discuss a difficult subject. Second, decision making does not always require that

the patient understand detailed prognostic information. Confronting patients with information they did not want is often a waste of time, and sometimes actively counterproductive. This is particularly true when it makes patients feel that the physician is not "on their side," or they feel "browbeaten" with the truth. Finally, although the patient may not want to talk about prognosis, the patient may be more than willing to let you talk to a surrogate about prognostic information. Ask if there is someone else you can talk to about these issues. This surrogate decision maker can help ensure that the patient's decisions are based in reality (or can step in for the patient).

1. *Try to elicit and understand why the patient doesn't want to know*. Although we observe many physicians simply backing off after hearing that a patient does not want to talk about prognosis, we find that understanding the patient's view can provide insight into the patient's reasoning and coping. In fact, the discussion about why the patient doesn't want to talk can be a useful trust-building step. For example, a physician could elicit this discussion by saying, "If you could help me understand your thinking about why you would rather not talk about prognosis, it will help me know more about how to discuss other serious issues." A patient might reveal that he is sad and worried that discussion will deepen his sorrow, or that he is concerned about how the information will affect his spouse, or that he wants his son to make the medical decisions – all issues with practical consequences for the physician.
2. *Acknowledge the patient's concerns*. Physicians should explicitly acknowledge whatever is on the patient's mind. This demonstrates that physicians understand patients' reasoning as well as their emotions.
3. *Ask for permission to revisit the topic*. Consider saying, "My experience is that people's interest in prognosis can change over time,

and so I'd like to be able to check in with you again about this in the future. And you should feel free to tell me if you decide you want more information. Is that ok?"

4. *Make a private assessment about whether prognosis might change patient's current decision making*. In some situations, physicians may feel that a patient has a misunderstanding of his prognosis that is contributing to poor decision making. Here, we recommend that physicians consider negotiating for limited disclosure or clarifying whether another person (i.e., designated proxy) should receive the information and make urgent decisions. The key question is, does the patient need the information now? If the physicians cannot identify a compelling reason to discuss prognostic information during the current session, then they should follow patient's wishes.

Patients may wish to designate another person to receive the information. With patients' permission, other family members may be given the information and use it to help them avoid making decisions based on unrealistic expectations.

In the exceptional circumstance, when you believe there is a compelling reason for discussing prognostic information and the patient does not identify someone else with whom you may talk, we recommend negotiating for limited disclosure. Start with a statement that explains why you think some information is needed: "I understand that you would rather not talk about prognosis today, and I want to respect that. And I also want to tell you that I see some reasons that prognosis is important for us to cover today – I think it might influence the decision you are thinking about. What do you think about that?"

In the previous table, a patient seems to decline to talk about prognosis, but after exploration is very interested in one specific piece of information.

WHAT HAPPENED	WHAT WE CAN LEARN
Dr. T: Are you interested in talking about the prognosis for this kind of cancer? Some people want lots of details, some just want the big picture, and others would rather talk about these issues with their family – what about you?	*Asking the opening question.*
Mrs. P: I know you can't tell me exactly how long I have.	
Dr. T: Well, that's true. The best I can do is give you my best sense based on statistics and averages. And I know that not everyone wants that.	*The doctor is trying to understand why patient doesn't want to know.*
Mrs. P: Only God knows what will happen to me.	
Dr. T: It sounds like faith is important to you.	*Acknowledging the patient's values.*
Mrs. P: Of course it is. My whole church is praying for me.	Her coping is linked to her faith.
Dr. T: It's great to have that kind of support.	*Showing respect for the patient's faith. Privately assesses that she doesn't have to know today.*
Mrs. P: I don't know what I'd do without it.	
Dr. T: You're lucky to have such a strong foundation. Now can I check in about something else? As you think about the future, what concerns you the most?	*Exploring the patient's concerns.*
Mrs. P: I'm hoping that this chemo that you have been talking about is going to work.	
Dr. T: I share your hope. Are you interested in talking about how often the chemo does work?	*Testing a hypothesis about what information the patient might want to know.*
Mrs. P: Ummm, ok.	
Dr. T: It sounds like you're not sure if you want to talk about that.	

WHAT HAPPENED	WHAT WE CAN LEARN
Mrs. P: Well, actually I do but what can you say? Isn't this in God's hands?	She appears to be experiencing a conflict between what she'd like to know and her faith.
Dr. T: Can I mention something? I think that talking about the chances that the chemo will work doesn't really affect someone's faith. I think you can have a lot of faith and still benefit from the information that we have gotten from clinical trials and research. Some people find knowing about what has happened to other people helps them plan.	*Explaining that knowing prognosis doesn't interfere with faith.*
Mrs. P: Well, that makes sense. So how often does the chemo work?	
Dr. T: So the chemo makes the cancer shrink for about 4 out of every 10 people that take it. That means that for 6 out of 10 people, the cancer does not shrink. We will check your CT scan after about 2 months of chemo to see if it is shrinking your cancer. And if the chemo is working, we will continue. If the chemo is not working, and the cancer is growing, then we're in a new situation with different chances. Does that all make sense to you?	*Double-framing the statistical information – talking about the proportion for whom the chemo works, and also the proportion for whom the chemo does not work.*
Mrs. P: You said 4 out of 10 people have their cancer shrink, is that right?	
Dr. T: Yes you've got it exactly. Is this anything like what you expected?	*Reinforcing the patient's understanding.*
Mrs. P: I'm going to tell my friends at church and have them pray for me and make sure I'm one of those four. I'm worried about this.	
Dr. T: I know this information can be hard to hear.	*Making an empathic guess about the patient's feelings.*

WHAT HAPPENED	WHAT WE CAN LEARN
Mrs. P: Yes, it is hard. But I'm glad you told me. Now I know what we are up against and what we need to ask the Lord to do.	
Dr. T: Do you have other questions now? Can I check in with you next time about any questions you might have about prognosis?	*Asking permission to revisit the topic.*
Mrs. P: No I don't need more just now, but I'll make sure to ask you if any come up.	

For patients who are ambivalent

In our experience, a substantial number of patients do not fit neatly into either wanting or not wanting prognostic information. These patients have mixed feelings about knowing their prognosis: they both want to know and don't want to know. Ambivalent patients can frustrate physicians because the patient may go back and forth in one visit, wanting the opposite of whatever the physician proposes. Ambivalence may also be subtle: patients might say verbally that they want to talk about prognosis, but simultaneously give other signals by changing the topic or looking away. The principle for dealing with ambivalence is to discuss it explicitly, allowing patients to talk about both pros and cons.

1. *Name the ambivalence*. Acknowledge that the patient has good reasons for wanting to talk and for not wanting to have the information. One might say, for example, "It sounds like you have some reasons that you want to know and reasons that you don't want to know. Do I have this right?" This step demonstrates to patients that we understand their individual complexity and are not going to try to close the discussion prematurely.

2. *Explore the pros and cons of knowing and not knowing*. Rather than trying to push the patient into either category, ask the patient to explain both sides of their dilemma. For example, a physician could say, "I hear that you have mixed feelings about this, so could you help me understand your feelings – on both sides – in more detail?" As the patient talks, a decision may become clear.
3. *Acknowledge the difficulty of the patient's situation*. In our experience, a great deal of ambivalence is rooted in patients' tension between wanting to know information for pragmatic reasons and being fearful of the emotional effects of the information on themselves and loved ones. This tension is not something that a simple communication technique can relieve. We recommend that physicians first try to demonstrate that they understand the patient's difficult situation and then articulate their willingness to simply be present with the patient in the situation. This requires both mindful attention and, verbally, an empathic response. In teaching this, we often observe that physicians treat the empathy as a clause before an action statement ("I know this is bad, but we can do another test, medication, or chemotherapy"), which undercuts the power of empathy. In these situations, we encourage physicians to *just* empathize with patients' difficult situations, and *wait* for patients to initiate the next step in determining how much information they need. At this point, physician empathy provides the support and safety needed for the patient to face a difficult reality, which is why empathy remains our single most useful communication practice.
4. *Consider outlining the options for discussion and consequences*. While empathy enables physicians to address most ambivalent patients, we occasionally take one further step. In this step, we outline the options for discussion (which are usually different levels of disclosure), and the ways in which these options will meet the patient's concerns. Talking about the consequences of the discussion may enable the

patient to come to a decision: "I could give you that statistical chance that the chemo would shrink the cancer, and that might give you a sense of whether you want to take a trip now, or wait until later."

What if the patient and family want different kinds or amounts of information?

What do you do when the patient wants you to be a cheerleader and the family needs the facts? If the wife asks explicitly about "how much time do we have?" while the patient is shaking his head, how can you balance the needs of both? This is especially difficult when being explicit about prognosis with a family member may include more information than the patient wants to hear. The key in this situation is to ask each person how much they want to know before you give the information. You could turn to the patient and say, "Your wife would like to hear more about what might happen when you get home, including your prognosis. Is this something that you want to know as well?" If the patient does not want the information, one can say, "Given that you are not really interested in all the information your wife wants, would it be ok if I talk to her separately after our meeting together?" This allows the wife to get the information she needs without burdening the patient. You may also want to tell the wife that it might be hard for her to share the information with the patient, so if the patient becomes curious, he could come back for another visit so you can give the news, to prevent leaving her with the burden of giving serious news.

Can a poor prognosis destroy hope?

First-person patient accounts of illness are riddled with stories of blunt physicians who destroyed hope, in our opinion, with information dumping. While physicians worry about "taking away" hope, studies indicate that when patients and families feel that the physician is

responsive to their information needs, that resulting conversations can make them feel hopeful in a particular way. This hope is not so much about a "thing" that physicians can bestow, but is more about the physician being present to help face an uncertain future. Your communication task is to show the patient through your responsiveness, empathy, and tact that you are capable of dealing with the hardest situations – it will cultivate the trust your patient needs to talk about statistics that no one would want to face alone.

The bottom line

Before you talk about prognostic information, spend a minute finding out what the patient wants to know.

Maximizing your learning:

1. Set aside a few minutes to think about one of the last times you talked about prognosis with a patient. What did you say, and what did the patient say? What did the patient do during the discussion? Did he or she look to a spouse, or begin talking about something else? What did the patient talk about, and what was the intent of that story? And what was the feeling you got from this – both the patient's emotion and yours?
2. Another kind of self-assessment question is to ask your patient: "Have I discussed the future in a way that helped you?" While this may seem similar to the "checking for understanding" step described earlier, this question is meant to focus on the process of the conversation rather than the accuracy of information delivery. Real success in discussing prognosis means engaging the patient in a process of growing understanding about their situation, understanding the patient's evolving information needs, and providing the information in a way that the patient can take it in.

FURTHER READINGS

Back, A. L., R. M. Arnold, and T. E. Quill, Hope for the best, and prepare for the worst. *Ann Intern Med*, 2003, **138**(5): 439–43.

Butow, P. N. et al., Communicating prognosis to patients with metastatic disease: what do they really want to know? *Support Care Cancer*, 2002, **10**(2): 161–8.

Christakis, N. A., *Death Foretold: Prophecy and Prognosis in Medical Care*. University of Chicago Press, Chicago, 2001.

Mack, J. W. et al., Hope and prognostic disclosure. *J Clin Oncol*, 2007, **25**(35): 5636–42.

Quill, T. E., R. M. Arnold, and F. Platt "I wish things were different": expressing wishes in response to loss, futility, and unrealistic hopes. *Ann Intern Med*, 2001, **135**(7): 551–5.

The, A. M. et al., Collusion in doctor-patient communication about imminent death: an ethnographic study. *BMJ*, 2000, **321**(7273): 1376–81.

6 BETWEEN THE BIG EVENTS

Dealing with the seemingly mundane

Trapped in the fixing mentality

For the most part, this book addresses pivotal moments in the trajectory of a patient with serious illness. This chapter is an exception – it's about the conversations that happen in between the big events. These conversations are more common than giving serious news; they happen all the time between patients and physicians who are willing to talk about living with a serious illness (and if you are reading this book, you're one of us). This chapter doesn't apply to a patient who has a car wreck, is taken to the ICU, develops multisystem organ failure, and dies there a few days later. The subset of patients we are addressing in this chapter are those who live for some time with the knowledge that they have a disease that will ultimately prove fatal, such as cancer, HIV, hepatitis, congestive heart failure. Patients with these illnesses live, as one put it, "with a sword hanging over your head."

For these patients, who have what we call "outpatient serious illness," adjustment to living with the illness, sometimes lumped with "coping," is a huge piece of work, and one that leaves many feeling

profoundly changed. We hear, for example, some of these patients talk about changing their priorities, experiencing love, finding deep friendships. Note that we are not advocating that physicians who deal with serious illness try to be therapists. But what we hear from both therapists and patients is that physicians can have an important role in fostering positive adjustments. Therapists and writers who think about illness in terms of narrative have shown that the stories patients create about their illnesses are incredibly influential, and it seems clear that some stories are better than others. Physicians both hear patients' stories and contribute to them, and working with stories can be an incredibly gratifying part of the job. It's a matter of becoming open to the possibility that a small conversation can have a big influence.

However, while we know this is possible, what we deal with on a day-to-day basis in our own practices is a lot of seemingly mundane stuff. The patient with end stage liver failure who is wondering about his prostate-specific antigen (PSA) level. The patient with metastatic colon cancer wanting you to look at a red spot on her ankle (no, it doesn't itch or hurt). The patient who is finishing adjuvant chemotherapy who wants another prescription for lorazepam, which makes you wonder if she is more anxious than you have realized.

These conversations may not be pivotal in the medical sense, but they can be incredibly important nonetheless. The turning point is in your seeing the opportunity to find out about your patient's clinical experience and to offer to share some of your clinical wisdom. We don't think this can happen all the time – we want to be realistic about the demands on your time, energy, and attention. But we do want to bring these moments to your attention, because they allow you to bring yourself fully into the therapeutic relationship, and that moment could be the most rewarding one of your day.

What makes these moments recognizable is that you feel called upon to fix something that isn't really fixable. Does ordering the PSA

for the patient with end stage liver failure really prevent prostate cancer? What happens most often is that the physician tries to fix things: we order the PSA because it seems like it will be quicker to add the lab test than try to convince the patient it is a waste of money. These kinds of conversations tend to leave both the physician and the patient vaguely unsatisfied. There is, however, another way.

Using your clinical experience to guide patients

This roadmap is meant for use when you feel you have clinical experience that would help guide a patient living with chronic illness. This is different than making a medical recommendation about what treatment would be best. In these situations, you are offering a suggestion or the possibility of a new story about how your patient can live with the sequelae of a serious illness.

1. *Ask the patient about their perspective on a symptom or concern*. Remember that the trajectory of adapting to the illness can be quite different than the trajectory of the disease pathology. (This may require a deep breath on your part, to give you a moment to step back from any irritation you might experience at the seeming irrelevance of the issue.) You may be an expert in the biology, but we are looking here at the patient's perspective and interpretation – even if it is not biologically accurate. So take a minute to ask what the patient's interpretation of the issue is. For example, you might ask, "Could you say what is bringing up the PSA test in your mind now? What have you been thinking about?"
2. *Empathize with the emotional content of the issue*. We most often begin with an acknowledgment about the impact of an issue ("This sounds like it's important to you"), although any NURSE statement could work. Give the patient some space to reflect, and consider floating a

hypothesis, for example, "Are you feeling differently about your own health now?" Or ask the patient, "Could you help me understand how you see this?"

3. *Offer your clinical experience as a way of creating new possibilities*. One way to do this is to ask the patient about their interest in hearing about other patients you've treated. For example, you might say, "Would you like to hear how other patients have dealt with this issue?" Your invitation and their acceptance signal a different kind of dialogue within the clinical encounter – you are drawing on your repertoire of past stories to give a patient a sense of what is possible. Offering a story in this way is not a promise that it will happen. Rather, make this story distinct from a recommendation (e.g., you should deal with issue by …). Don't impose your experience on the patient – just offer it.
4. *Follow-up by asking the patient what he is taking away*. We would consider success here as having the patient leave with some new interpretations, ideas, or possibilities. But another way to look at this is to ask, "Did the person come away from this conversation feeling bigger or smaller?"

A few examples of this roadmap follow. These are not meant to be exhaustive – we intend simply to give you some ideas about possibility.

Completing planned disease-modifying therapy

For Ralph, a lawyer with colon cancer, coming to the infusion clinic for his last dose of adjuvant chemotherapy was a complex event. On one hand, he was looking forward to putting the side effects of chemo behind him, and he was anxious to get back to full-time work, and

looking forward to a vacation. On the other hand, he was also worried about not doing as much to fight off the cancer, and while the infusion clinic took a lot of time, it gave him a sense of security that all these people were working to keep his cancer from returning. For a patient like Ralph, simply raising the issue gave him a chance to plan.

WHAT HAPPENED	WHAT WE CAN LEARN
Dr. B: Hey, congratulations on your last dose of chemotherapy! You've done a great job dealing with it all.	*Praising the patient (notice how this is different from telling the patient he should be happy) and marking completion as a milestone.*
Mr. S: Thanks doc, it's been tough. But I've gotten through ok.	
Dr. B: Yes, it is tough. Do you have any concerns about finishing up the chemo?	*Acknowledging the patient's experience of "tough."*
Mr. S: Do you mean is the cancer going to come back?	
Dr. B: Well, people tell me that concern is always in the back of their minds. Could I mention some other common things that patients of mine have noticed when they finish their chemo?	*Offering clinical experience.*
Mr. S: Yes of course. Like what?	
Dr. B: One thing is that often people have mixed feelings about finishing chemo. They're glad to be done, of course, and they're a little nervous about not having chemo because they felt like it was protecting them.	
Mr. S: Actually, that describes me exactly.	
Dr. B: Tell me more …	*Exploring, and offering further conversation.*

This conversation resulted in a bit of clarity for Ralph, that enabled him to understand his situation, and allowed his doctor to discuss a couple of practical follow-up actions. Ralph heard the plan for colonoscopy in a few months, and follow up visits every 3 months; he also got a referral to a physical therapist to learn some abdominal strengthening exercises to compensate for the strength loss incurred by his abdominal surgery. Dr. B used the completion of therapy visit to remind Ralph of what he could do to participate in best follow-up, and also to address a common posttreatment issue for patients who have had abdominal surgery. In oncology, these issues are now grouped under the term survivorship, which focuses on long-term side effects. (The scope of survivor care goes well beyond the scope of this book, and addresses situations somewhat unique to cancer medicine. The communication issue we are discussing in this chapter is just one survivorship issue.)

Living with long-term side effects of therapy

For Margie, a woman with advanced COPD, starting home oxygen put her "in a different place" with her illness. She was grateful that the oxygen allowed her to go out more and remain independent, but she was also a little resentful that she was now "tethered" to her oxygen tank. Her pulmonologist had seen patients struggle with this kind of trade-off before and recognized the initiation of home oxygen as a clinical trigger for a key communication task: asking about living with the side effects of therapy – both physiological and psychological.

WHAT HAPPENED	WHAT WE CAN LEARN
Dr. C: How have you been doing with the oxygen?	*Asking an open question, but one that is focused on a particular issue.*
Mrs. D: It's helped me. I can go to the store and not worry so much.	

WHAT HAPPENED	WHAT WE CAN LEARN
Dr. C: What were you worried about?	
Mrs. D: That I'd get half done with my shopping and be so out of breath, then what would I do?	
Dr. C: I'm glad to hear that the oxygen helps with that. I know independence is important.	*Acknowledging emotional value of independence.*
Mrs. D: It is, you know. I'm my own person.	
Dr. C: Some of my other patients tell me that although the oxygen helps them breathe that they also don't like it. Have you had any thoughts like that?	*Offering clinical experience, asking the patient to comment.*
Mrs. D: Well, I don't like the way it looks.	
Dr. C: How so?	*Exploring (rather than just agreeing) unearths another level of the patient's experience.*
Mrs. D: It makes me look like an invalid.	
Dr. C: You're feeling that people look at you differently?	*Reframing the self-judgment of "invalid" to something about what other people do.*
Mrs. D: I get some funny looks, all right.	
Dr. C: I'm sorry to hear that. That doesn't help, does it? Sometimes I've had people say that they would rather not get the looks, even though their breathing is worse without the oxygen.	*Supporting empathically.*
Mrs. D: What can you do? (sighs).	
Dr. C: Well, I can't change the way it looks, but it's an important issue. It's important because I want you to get the benefit of the oxygen. Could we think about this some more? I work with some other clinicians, like our nurse specialist who could follow up on this issue. Would that be ok with you?	*Offering resources as the nurse has more time and expertise about this issue.*

Reinvesting in the future

For Kate, finishing her treatment for inflammatory breast cancer brought up something she hadn't expected: she felt stuck. Not sure about whether she could make plans because she knew the chances for cancer recurrence were significant, not something she could ignore, and also feeling like she couldn't just "go back" to her old life. In the example below, Kate's oncologist recognizes the trigger for a query about reinvesting in the future when she says something about living with uncertainty. The physician's task in dealing with uncertainty now that treatment is over is different than when Kate was starting her treatment, because the clinician's goal 8 months ago was to get her through a rigorous series of treatments. Now the clinician's goal is to help her live fully now – for whatever length of time it turns out to be.

WHAT HAPPENED	WHAT WE CAN LEARN
Ms. E: I know I'm done with my treatment, and I'm glad to be done. But I'm not sure about what's next.	
Dr. D: Tell me more what you're not sure about.	*Exploring what the patient meant by "not sure what's next."*
Ms. E: It's hard to explain. After facing the cancer and getting through the treatment, I feel like a different person. I'm not sure I want to just resume my old life. I don't think I can. But I feel stuck about what I should do.	
Dr. D: I'm wondering if it is hard to make plans because you're not certain about what could happen with the cancer.	*Reframing the patient's words to acknowledge emotion of "uncertainty."*

WHAT HAPPENED	WHAT WE CAN LEARN
Ms. E: I think that's part of it. It's like I'm waiting for the other shoe to drop.	
Dr. D: Yes …	*Creating a silence that invites exploration by turning toward the patient, looking at her, smiling.*
Ms. E: Sometimes my body feels like a time bomb, just waiting to go off.	
Dr. D: That's a powerful image – like you don't quite trust your body?	*Acknowledging the emotion and exploring.*
Ms. E: Yes, that's it (eyes welling up).	
Dr. D: I could see why you would feel that. I wish I had a pill to fix it (smiles). Wouldn't that be nice?	*Understanding, then using an "I wish" statement.*
Ms. E: No kidding.	
Dr. D: I do think there are ways you can learn to live with the uncertainty though. So that it could feel not so much like a time bomb – more like an occasional unwanted visitor. I have some ideas about this based on what I have learned from other patients – would you like to hear?	*Offering clinical expertise.*

Dr. D has suggested that Ms. E could work with her feeling of being threatened by uncertainty and eventually live in a different way with it. In doing so, Dr. D articulates a way forward, yet does not assume he would be the one to do this work with Ms. E, and in fact, he will refer her to a psychologist for this specific issue. This example illustrates how front-line clinicians can uncover important issues without feeling as though they themselves have to fix or address them.

THE POWER OF ACKNOWLEDGMENT

I had taken care of a woman with Crohn's disease for several years, and I was frustrated. She always had multiple physical complaints and a depressed affect. Nothing I did made her feel better. One day, though, she came into the office looking nicer than usual. Yet, when she spoke, she conveyed the same complaints I had heard repeatedly in the past. Rather than respond to, or acknowledge these concerns, I focused on how good I thought she looked. The next week, I found a brief note from her in my mailbox letting me know that she had switched to another physician. I called her immediately and asked her what had happened. She told me, "When I visited you last week, I told you how bad I felt and all you did was tell me how good I looked. Sure, I try to dress up when I go out or see the doctor, but inside I was still feeling lousy. I didn't think that you saw that." She was right. I so wanted her to feel good that I thought that by praising her it would happen. What I missed was that she wanted me to acknowledge her pain and be there for her, whether or not I could fix her. I lost a patient, but learned an incredibly valuable lesson.

The bottom line

Offering your clinical experience can allow you to guide patients toward their own healing.

Maximizing your learning:

1. What are the clinical experiences that you have had that would be useful to other patients? It might help to remind yourself about what in your experience you'd like to share. Remember that positive stories about what is possible are much more powerful than negative stories about what to avoid.
2. Ask a colleague for some feedback – if you referred a patient to a psychologist or nurse, ask them if the patient seemed prepared for the referral. Then think about the feedback. How was it valuable?

Would you ask that person again? Are there other instructions you would give? Remember that the quality of the feedback you get is partially dependent on your instructions.

FURTHER READINGS

Charon, R., *Narrative Medicine: Honoring the Stories of Illness*. Oxford University Press, New York, 2008.

Frank, A., *At the Will of the Body*. Mariner Books, Boston, 2002.

Hewitt, M., S. Greenfield and E. Stovall eds., *From Cancer Patient to Cancer Survivor: Lost in Transition*. The National Academies Press, Washington, D.C., 2005.

Kleinman, A., *The Illness Narratives: Suffering, Healing and the Human Condition*. Basic Books, New York, 1989.

Rowlasnd, J. H. and K. M. Bellizzi, Cancer survivors and survivorship research: a reflection on today's successes and tomorrow's challenges. *Hematol Oncol Clin North Am*, 2008, **22**(2): 181–200.

7 CONDUCTING A FAMILY CONFERENCE

With a group, you multitask

When does a family conference make a difference?

How you deal with a patient's family can make or break the relationship you have with the patient. Plus, the family can help you: they can repeat things, reinforce your message, clue you in on what's important. In the process, they will be better at the caregiving they take on, cope better, and will feel more rewarded for their efforts.

At the right moment, getting the whole family (and the patient if possible) into a room can be hugely beneficial. Most often this happens in the hospital, but this is a tool you can use also in an outpatient clinic. However, family conferences take time, effort, and a lot of people, and research in this area doesn't tell us when the effort and expense required for a family conference actually pay off. So, when are they worthwhile? One trigger for a family conference is when there is serious news to discuss (e.g., the goals of treatment need to change from curative to palliative) and the patient wants to have the family involved, or the patient is too ill to participate. Another trigger is when the patient is too ill to participate in decision making, and the family members disagree about the decisions that need to be made.

We are not saying that you should talk with family members only in these situations. However, in this chapter, we are focusing on the "big" family meetings where you are trying to get all the family members together, provide information, and try to determine the overall goals of therapy. The roadmap is also useful for other encounters where family members are involved. One more note: we use the term "family" to refer to all people who are emotionally intimate or biologically connected to the patient. Thus, a patient's "family," for our purposes, may include an unmarried partner, a close friend, a second cousin – in addition to a spouse, child, or parent.

While the family conference is well established as a communication tool, we have seen them used well and used poorly with nearly equal frequency. For every doctor who views the family conference as a panacea, another wearily disagrees, assuming that it will yield little progress. What can we do to maximize the value of the family conference?

The principles for talking to family members remain the same whether there is one family member or many. However, meeting with a group of people raises some unique issues we have not discussed in other chapters. Multiple family members means multiple agendas, emotions, and values and, in situations where patients are unable to speak for themselves, families may need to deal with surrogate decision making.

Family conferences challenge us because (1) families bring the complexity of their own relationships and interactions to the meeting, (2) family members each have their own interests, (3) family members have individual emotional needs, (4) family members may have different preferences for information or decision making, and (5) family members may disagree about the right course of action.

Family therapists tell us that families are more than a collection of individuals. Families are independent organisms with their own way of

functioning. Some families talk things out calmly, some yell and scream, and others avoid conflict altogether. Family members also learn and assume their roles in the family. When these roles change out of necessity, others may not know how to react. For example, if before becoming ill, the matriarch was the family decision maker, her daughter may feel insecure and anxious about making the monumental decision of withdrawing the matriarch's life support.

Creating a neutral discussion zone

We don't expect you to become a family therapist. But recognizing how family roles and processes function may help you understand with whom to talk first, who shouldn't be left out, and how to frame the issues.

CHALLENGE	COMMUNICATION TOOL
Family dynamics	Inquire about how the patient's role has changed. Find out how the family makes decisions.
A troublesome family member	Remain neutral and avoid taking sides.
Divergent opinions	Name the disagreement.
Strong emotions	Acknowledge the emotion in the room.

Two background questions are especially useful. First, inquire about the patient's role in the family. For example, you could ask, "In talking about these decisions, it would help me to know more about your father's relationship with all of you. Do you generally get along? Is he the decision-maker or does he generally follow along with what others want to do?" Second, follow up with questions to help you understand how the family makes decisions. Some useful questions include "How could your family best make a medical decision and feel good

afterward?" or "Who needs to be involved and what should the process look like?" "Do you have any worries about how your family will deal with what is going on?" While we realize that you do not always have the luxury of knowing the answers to these questions before the family conference, remember that a social worker, psychologist, or nurse might know the answers already.

To create a neutral zone amidst the family dynamics, remain neutral in family interactions. Recognize the different family members equally so as not to ally yourself with one person or one side of the family. It may be hard to do this, particularly if you feel that one family member is being unfair, or even cruel. The family dynamics, however, predate the patient's illness and reflect lifelong patterns of interaction. You will not be able to change these patterns in a single brief conference, and if you try to change them, you're setting yourself up for failure. If everyone starts fighting, you might say, "I can see that you all have some disagreements on a number of issues. I wonder if you could put these aside for now, so that we can focus on what's going on with your mother." The principle is that you are there to facilitate discussions focused on the patient's values, not to help the family communicate more effectively.

However, when it comes to caregiving, you should take a secondary role. Let family members care for each other before you jump in. If one of the children begins to sob uncontrollably, it's better for her spouse or sister to hold her than for you to step in and assume that role. (This is just another example of the above principle of respecting the previously established family dynamics.) When you see constructive displays of empathy from family members to each other, acknowledge and reward them. If, however, the family members are not caring for each other, you should definitely step in with empathy – besides the value associated with your responding to their emotions, there may be value for the family in how you model empathy.

When families need to decide for a patient

When patients are unable to participate, the family members are ethically and legally empowered to serve as the surrogate decision maker. In talking to them about the medical choices, we have noticed some common pitfalls. The first of these is asking family members to decide on life-sustaining treatment for a patient, rather than asking them to assess what their loved one would want. This is a subtle, but important difference. In making decisions for the patient, family members often confront their own hopes and fears about the patient's illness and death, and if the question about preferences is not anchored specifically to the patient, the family may become even more anxious. We recommend asking the family to represent what the patient would say: "If your mother was sitting in a chair with us, what would she say about this?" One study indicates that this question yields more accurate answers, and in our experience, asking what the patient would want lifts a bit of the responsibility and guilt from the family's shoulders.

PITFALL	COMMUNICATION TOOL
Asking the family to decide for a patient ("What do *you* want us to do?").	Ask the family what the patient would have wanted ("If she could talk for herself, what would she want us to do?").
Focusing on a single legal decision maker ("You're the proxy, we follow what you say").	Respect other decision-making models – like consensuws ("How does your family make decisions like this?").
Overlooking stresses of caregiving ("I don't know if you've been here at the hospital").	Explore stresses and identify support services ("How are *you* coping?").

The second pitfall is rigidly focusing on a single, legal, surrogate decision maker. In our experience, despite laws that give a hierarchical order of surrogates, many families make decisions for their loved one

based on consensus. Even if the husband is the legal surrogate, the doctor typically meets with the entire family about what is going on with the patient. And, while the husband may make the "final decision," he often wants to get the family's opinion and, if possible, agreement. We recommend that physicians ask, instead, how the family wants to make the decision and honor their preference if possible.

The third pitfall occurs when clinicians overlook the stress of caregiving. Family members in these scenarios are always stressed, sometimes anxious, and occasionally depressed. In one large study of patients with life-threatening diseases, 40% of families spent all of their savings caring for the patient. In addition to this huge financial burden, family members who have experienced the life-threatening illness of a loved one are at risk for posttraumatic stress disorder, and this risk rises with the length and complexity of the illness. Think of the family as stressed individuals who will function better if supported. Ask them how they are doing and what you can do to help them get through their loved one's illness. Often the family has simple problems that you can refer to the social worker (e.g., help with a letter to their boss, or paying for parking). Families are very appreciative of your simple efforts to help them and view them as evidence of your trustworthiness.

Similar to your interactions with individual patients, empathizing with family members' emotions is critical to creating a neutral zone for productive communication. In our experience running family meetings, the most common emotion we see is guilt. Families feel guilt about "pulling the plug" on a loved one. You can address this by asking for the patient's view as we discussed earlier and allowing some time and space for the anticipatory grief they will experience as death approaches. Sometimes grief is not so much the issue as worry that they are abandoning the patient. After all, your family is supposed to take care of you, and American culture values intervention (doing something is better than doing nothing). Thus, the default decision for most families is to

want everything possible to improve their loved one's health. The language you use here is important: asking the family if they want to be "aggressive" or do "everything" implies that palliative care is "giving up." Similarly, talking about "withdrawing care" or "stopping life support" may heighten worries that the family is abandoning the patient.

Roadmap: conducting a family conference

Notice that this roadmap has many parallels to the roadmap for giving serious news (Chapter 3).

1. *Prepare the people and the messages for the conference*. Who should be invited? In general, all family members who want to be present should be able to attend. The only exception to this policy would be if the patient said, while competent, that certain people should not be included. Inviting some family members but not others seems to be taking sides and decreases one's ability to be an impartial patient advocate. A brief meeting of the participating health care providers before the conference will enable you to deliver a clear and consistent message that will not be undercut by another provider. One person should facilitate the meeting (this is usually, but not always, the physician) to recognize who should speak at any one time. A room with some privacy enables everyone involved to speak more freely.
2. *Introduce all participants and the purpose of the conference*. If you are facilitating, ask the other clinicians to give their names and roles in caring for the patient; ask family members to state their relationship and caregiving responsibilities. The facilitator might outline the purpose by saying, "I want to tell you how your dad is doing medically. I also want to make sure that you understand what we are doing for him and what we're watching for. Finally, we want to learn from you his values and goals so that we can make decisions that are the ones he would make if he could be with us right now. Are there any other things you

want to make sure we discuss?" Families often respond to this question with a list of specific questions about what is happening or will happen. We suggest that rather than jumping right in and answering these questions that you acknowledge their importance ("Those are great questions, let me write them down") and try to assess what the family knows before trying to answer them ("I will make sure I answer your questions. I wonder, if first you could tell me what other people are telling you about what is going on with your mom?").

3. *Assess what the family knows and expects*. Ask the family what they've been told about his illness, and what they have observed. This enables you to assess how well they understand the medical situation, how they are doing emotionally, and how you should frame your summary of the clinical condition. If a family says, "We think he is dying," it is likely to lead to a very different conversation than if they say, "The doctors say he is not likely to get better, but we are praying that he gets better. He is such a fighter." Notice the emotion data in what the family says. Ask them if they want detailed information and whether they find statistical information helpful.
4. *Describe the clinical situation*. Begin by asking permission to share your view. Start with the "big picture." While you may want to name specific parameters that are being monitored, skip detailed pathophysiology. The entire overview should take no more than a couple of minutes. If you are longer, you have probably not prepared a clear enough message prior to the conference. Check for comprehension after you have finished by asking, "Does my explanation make sense? Is there anything that is not clear?"
5. *Ask each member of the family for concerns*. After providing information, it is important to ask explicitly for questions and concerns. Different family members may have different concerns. If possible, we ask, "What other questions or concerns do you all have?" until there are no more questions. If one person seems to dominate,

invite other family members to speak ("Can I see if any other family members have questions?"). Acknowledge the emotional content of the family's concerns (see "Responding to emotions with words" in Chapter 3). Finally, it may help to ask if there is anything you can do to help the family members themselves; "What can we do to help you to get through this difficult time?"

6. *Explore the patient's values and how they should influence decision making*. As we noted earlier, focus on what the patient would want (e.g., "If your dad was sitting here and could hear what we are saying, what would he say?"). Some family members find this question difficult to answer; we find that while they know what their loved one wants, what they know the patient wanted conflicts with what they would want for themselves. For example, a daughter might say, "My dad would never have wanted to live like this but I don't want you to stop." While telling you that her dad would not want treatment focused on existence with this quality of life, she is also telling you that she feels guilty over being asked to make a life and death decision. Acknowledge this, and remind the surrogate that her role is to tell you what her dad would want by saying "I can understand that. I appreciate your telling me what your dad would say, so we can respect his values. And I know it's hard when you just want him to stay alive." Often, such a statement will lead to a discussion of the daughter's guilt and conflict, which may then lead her to let go of her own agenda and honor her father's.
7. *Propose goals for the patient's care, and be prepared to negotiate*. We think physicians in these conferences should make clear recommendations based on the patient's values. Propose a plan that honors the patient's goals first. Then you may want to talk about the therapies that don't fit. Don't start with a long list of therapies you want to withhold. (We cover this in more detail in Chapter 10.)
8. *Provide a concrete follow-up plan*. Summarize the messages that you want the family to take away from the meeting. If the discussion

focused on the goals of care, the summary should focus both on consensus decisions and on areas of disagreement. In addition, talk about milestones that may affect future decision making. For example, if you decide upon a trial of antibiotics, then talk about what criteria will be used to know whether or not the antibiotics are working. It is also very important to specify the next time you will talk to someone in the family ("I'll give an update to whoever is here for rounds tomorrow"), so they have some sense of continuity.

A challenging moment in a family conference

This exchange picks up at step 5 of the roadmap.

WHAT HAPPENED	WHAT WE CAN LEARN
Dr. A: Given the medical situation I have just described, what concerns you most?	*Eliciting family concerns.*
Mrs. F (wife): I'm just worried about whether he is going to make it.	Notice the invitation to discuss death.
Mr. F (son): We have to think positive. He *is* going to make it, isn't he, doc?	
Dr. A: I just wonder if you two deal with the uncertainty in different ways.	*Noting that family members have different reactions rather than supporting one viewpoint at the expense of the other, which would be taking sides.*
Mr. F: That's certainly true.	
Dr. A: Could you tell me what you think Mr. H would say if he were sitting here?	*Eliciting patient's values using specific instructions to the family.*
Mrs. F: I think he would say that if he could only be alive like this he would not want it.	

WHAT HAPPENED	WHAT WE CAN LEARN
Dr. A: [to wife] Ok. [to son] What do you think?	*Inviting each family member to participate.*
Mr. F: He would probably want to be like this only if he had a chance to survive.	
Dr. A: Do you mean, if he had a chance to survive and improve enough to get off the breathing machine?	*Asking a clarifying question.*
Mr. F: Yes. He's a fighter though.	
Dr. A: [looking at wife, then son]I appreciate your honesty since I have not had the chance to talk to him, really. [to son] It sounds like you know him as a fighter, and that you want to help fight for him.	*Expressing gratitude, and reaffirming importance of family's role in decision process.*
Mr. F: That's absolutely right!	
Dr. A: Could I suggest some things that you could do to help him?	*Deciding not to confront the son, but rather to form an alliance first.*
Mr. F: Yes.	
Dr. A: I think it would be very comforting for him for you to spend a little time talking to him each day – put your hand on his and tell him about your day. You could also tell him about your daughter. You can even tell him your version of what the doctors think. That kind of touch and talk are enormously soothing, and he could only get that from you.	*Identifying strategies to enable the family to be present with the patient.*
Later …	
Dr. A: I think I understand better now about Mr. H's views and values, and also about your concerns. Could I now talk about what I think would be the next best step medically, and get some input from you both?	*Signposting a new direction in the conversation, and asking permission to proceed.*

VALUE SKILLS

The acronym "VALUE" was coined by J. Randall Curtis, and encompasses all of the skills outlined in this chapter. In a large ICU study, VALUE was part of an intervention that improved family satisfaction and decreased their distress. The acronym stands for: Valuing and Appreciating what the family said ("I really appreciate your coming to the meeting today." "Your help in telling us about your brother's values is really important in enabling us to develop the best plan"); Acknowledging the family's emotions ("I imagine that this is not what you wanted to hear"); Listening and Understanding the patient as a person ("Tell me what your Dad enjoyed before all this happened?" "What would your dad think of all this?"); and Eliciting questions ("What concerns do you have?").

The bottom line

Remember that each family member needs some individual communication with you, and also that the individuals in a family collaborate to form a unit with a life of its own (which you should observe and not interfere with).

RECOGNIZING WHAT A FATHER GAVE TO A SON

I was asked to talk to the family of a patient who had been in the MICU for 9 months. This family, I was told, was very resistant and kept saying that they wanted "everything" done; I asked the two sons, "What do you think your dad would want if he was sitting here and could hear what everyone was saying about his illness?" One son immediately said, "He would never want this. He was very clear that if he could not go fishing and be active, that this would be a horrible existence." The other son piped in; "But we can't tell you not to do something that might help him. He was always there for us." Knowing this, I was able to acknowledge how much they cared for their dad and that they had done everything that might help him. What they needed to do now, I suggested, was to attend to their father's wishes. Rather than asking what surrogate decision-makers "want," this story reminds me that I need to orient surrogates to their role – which is helping me understanding the patient.

Maximizing your learning:

1. This chapter contains a large number of potential skills to practice. One advantage of working on family conference skills is that often there is another clinician present who can give you feedback. If you have a chance, speak to the clinician before the conference and prepare that person to give you feedback. Tell them you are trying to improve your communication, and ask them if they could give you a couple of minutes of feedback after the conference. Tell them the skill you are trying to practice and what you want them to look for. Finally, tell them that you find the most helpful feedback to be descriptive – what did you say and how does the other person respond?

FURTHER READINGS

Goold, S.D., B. Williams, and R.M. Arnold, Conflicts regarding decisions to limit treatment: a differential diagnosis. *JAMA*, 2000, **283**(7): 909–14.

Hammond, S.A., *Thin Book of Appreciative Inquiry*. Thin Book Publishing Company, Bend, Oregon, 1998.

Lautrette, A. et al., A communication strategy and brochure for relatives of patients dying in the ICU. *N Engl J Med*, 2007, **356**(5): 469–78.

McDonagh, J.R. et al., Family satisfaction with family conferences about end-of-life care in the intensive care unit: increased proportion of family speech is associated with increased satisfaction. *Crit Care Med*, 2004, **32**(7): 1484–8.

Spiegel, D. and C. Classen, *Group Therapy for Cancer Patients: A Research-Based Handbook of Psychosocial Care*. Basic Books, New York, 2000.

Torke, A.M. et al., The physician–surrogate relationship. *Arch Intern Med*, 2007, **167**(11): 1117–21.

8 DEALING WITH CONFLICTS

From "Who's right?" to "What's our shared interest?"

Looking for value in differing points of view

Up to this point, we have talked about communication meant to educate, support, and empower patients, with the underlying assumption that beneath it all, the clinician and patient can agree on the next step. But what do we do when physician and patient don't agree? Consider the patient with metastatic colon cancer progressing despite fourth-line chemotherapy who wants you to give another regimen that you think will be a waste of time. Or the ICU team who wanted to give up on someone you thought still had a chance.

These are uncomfortable situations for most physicians. The term "conflict" may be overkill for many disagreements but physicians often back off at the smallest signal of conflict. Most of us just don't like to argue. Often we assume that disagreement means that our expertise is being called into question, and that makes us react either by saying, "I can't do that" or by withdrawing and deferring to "whatever the patient wants." Neither of these two reactions allows us to discuss our

differences of opinion, explore the options, and come up with an agreement that we all could live with.

How do better communication skills help address a conflict? They do so by shifting the focus from "who's winning?" to "what's at stake for the patient." In complex medical situations, the different participants – physicians, nurses, other clinicians, patients, and family members, all need to contribute – and their different kinds of knowledge and different perspectives will probably not all point in the same direction. Physicians usually assume that conflict is undesirable and destructive – which is true if it's handled poorly, because the bad feelings that result tend to obscure the rest of the conversation. Yet conflict handled well can be productive, and the clarity that results can lead to improved decision making.

How to recognize when you're in a conflict?

We often fail to recognize that a conflict is unfolding, or that it's serious, until very late. By then, frustration can lead us to say something that we later regret. The earlier you can detect that another person does not agree with you, the earlier you can shift your approach. A variety of early clues can help you recognize a conflict early. One such clue is when you begin to feel that you are talking in circles and the conversation is going nowhere. Another is when you begin to make internal negative judgments about the other person – they're "not getting it," "clueless", or "in denial" – and, as a result, you are feeling angry or frustrated. Yet a different clue is when you find yourself feeling fed up and wanting to shrug your shoulders and say "whatever," just to be able to withdraw from the situation. When we see these signals, we know we are about to get stuck in an unproductive place. At that moment, it is probably best to (1) stop what you are doing (it's probably not helping anyway) and (2) avoid saying the first thing that comes to mind (which would make you feel good, but will probably only make things worse).

What helps you handle conflict?

Conflict requires you to step back from your instinctive reaction and move toward a nonjudgmental curiosity. Cultivating that nonjudgmental stance is hard, especially when you are trying to present your observations, your expertise, and your clinical judgment. But we are not asking you to step away from what you think is right, we are only asking you to stop for a minute and listen to the other person. Ask yourself: why is this otherwise well-meaning person wanting something different in this situation than what I want? The "well-meaning" attribution is important. To deal with this successfully, you cannot afford to frame the other person as an idiot because people will pick up, perhaps from your nonverbals, that you are dissing them. You will not be successful if the other person feels dismissed. If you come across as arguing your point over and over (which we find ourselves doing when the other person "doesn't get it"), the other person will rapidly stop listening. They do this because they think that you don't get it, and don't have enough patience or courtesy or respect to listen to what they have to say. So take a deep breath and summon your most patient self. Because if this sounds like it can take some time, consider the alternative. A full-blown conflict will consume way more time and energy than what we're suggesting.

A roadmap to dealing with conflict

This roadmap is different from the others in this book because it isn't about helping someone else find their path; it's about helping you find your path when you're at odds with that someone, and it's a different role for many physicians.

1. *Notice there is a disagreement*. We have a broad definition of conflict: a conflict is a dispute, disagreement, or difference of opinion related to patient management, involving more than one individual,

and requiring some decision or action. Thus, absence of shouting does not rule out conflict. You may notice repeated requests for the same thing, an edge of sarcasm, a bit of body language (e.g., subtle eye rolling or sideways glances). The cost of ignoring these more subtle gestures is that the real issue will be discussed when you are not around – without your input. You may notice that you feel irritated, or bored ("this again?"), or exasperated – your internal signals may be the most useful sensors for noticing conflict.

2. *Find a nonjudgmental starting point*. The key to intervening in a conflict is to raise the issue without attacking the other person. You may need a minute to get ready (data from marital arguments show that this actually takes 20 minutes, so don't underestimate your irritability). You may find it valuable to ask yourself what we call "the humanizing question," Why would a decent, rational, logical person want what they asked for (or do what they just did)? The purpose of this question is twofold: you pause before rushing to judgment, and you create space for the other person to speak. Then restart the discussion by finding a starting point that just names the topic in a nonjudgmental way – not "I want to talk about your attitude" but "I feel like we're talking about what the best treatments would be, could we start here?".
3. *Listen to and acknowledge the other person's story/concern/viewpoint*. Turn your full attention to the other person, and turn off your own concerns for a few moments. If you are mentally preparing counterarguments, you are not really listening. Douglas Stone describes three things to listen for: (1) their story about what has happened; (2) the emotions (theirs and yours) generated by what happened; and (3) their view of their identity – how does it shape their views? Your goal here is not simply to mirror their words back to them; you need to provide them with evidence that you understand their view and their emotional reaction.

4. *Identify what the conflict is about, and try to articulate it as a shared interest*. Now you can talk about your views and concerns. Use language that focuses on the problem, not on the people. Describe the issue so that it is a shared interest. This may require some reframing, and reframing topics from emotionally charged to a shared interest takes practice. Rather than telling a patient, "You're wrong that the treatment on the Internet would help you," you might try, "I want to make sure you have access to the best treatments." A handy tip for reframing is to shift the focus from the person "you're wrong" to the interest "the best treatments."
5. *Brainstorm options that address the shared concern*. In conflicts between a physician and patient, it is often the physician's willingness to consider alternatives and talk about them that proves to the patient that you are willing to address their concerns. The key to talking about options is to simply list and explain what they are without saying which one is your first choice. Let the patient take them in and think about how each option meets the shared concern. One option we find useful to offer in situations where there is disagreement about whether a new treatment will be worthwhile is a time-limited trial of a medical intervention.
6. *Look for options that recognize the interests of everyone involved.* As a physician, you routinely make judgments about the best medical care, and we routinely equate "best" with most efficacious. Negotiating effectively might mean that you need to consider what would be "best" because it meets a patient's or family members' needs even though another option might be more biologically efficacious. There may also be options that you think are not reasonable. Coming to agreement on the action to take as a result of the conflict requires that you be clear for yourself about which options you can live with.
7. *Remember that not every conflict can be resolved*. Even using these principles, you will run into some conflicts that you cannot resolve.

Consider then finding a third party that you both respect to moderate the discussion. An ethics consultant, someone from quality management (they often have people who mediate disputes that patients and families have with clinicians), or a palliative care consult may help – but it depends on their skill.

WHEN TO DROP THE "BUT"

I was in a family meeting where the doctors kept saying, "We know you want your loved one to get better, but he is really, really sick." Afterward, the family complained that the doctors did not want their loved one to get better, that they did not feel the doctors were on their side. I remembered a conference where a speaker pointed out that the word "but" essentially discounts everything preceding – it was an amazing revelation. So I reframed the issue by saying, "it sounds like the doctor says he is really sick and yet you still hope that he will get better." This worked much better. The family felt that I understood them.

The following exchange, between a physician and a woman with advanced peritoneal carcinomatosis and her partner, illustrates the roadmap.

WHAT HAPPENED	WHAT WE CAN LEARN
Ms. J: I've been thinking that I'd like to go to the hospital.	
Dr. A: Tell me what's been going on?	*Noting the disagreement internally, then making a conscious effort to find a nonjudgmental starting point by exploring.*
Ms. J: I'm uncomfortable because of the fluid in my abdomen. I think I need an iv, because I can't eat – I feel too full.	

WHAT HAPPENED	WHAT WE CAN LEARN
Dr. A: It sounds like you are having a tough time.	*Listening to the patient's story about what's happened, using empathy to show that he understands the patient's viewpoint.*
Ms. J: Well, yes.	
Dr. A: I think we could do a better job with all these issues.	*Trying to articulate the shared interest – for better symptom control.*
Ms. J: That's why I want to go to the hospital.	
Dr. A: Could you say why you are thinking about the hospital, versus outpatient treatments?	*Eliciting patient's reasoning.*
Ms. J: I think things will happen faster, that they will take care of me.	
Dr. A: It sounds like we need to focus on making you more comfortable. Could I make some recommendations at this point? I will talk about the pros and the cons of going to the hospital, ok?	*Asking permission to present options that meet the shared concern.*
Ms. J: Ok.	
Dr. A: If we did a bit more evaluation today, there are some medicines we could start now to make you more comfortable, so all of this could start sooner than having you go to the hospital. The pros of going to the hospital are that there are lots of nurses and doctors around to help you; the cons are that they would probably discharge you after only a day, and the hospital doctors would expect the rest of the treatment to happen at home.	*Presenting the option of outpatient intervention, also the option of inpatient intervention.*
Ms. J: What could we do right now?	
Dr. A: Here is what I think …	*Having negotiated the conflict, Dr. A makes medical recommendations now that Ms. J is more receptive.*

How conflicts with other clinicians differ from conflicts with patients?

When working with patients and families, conflict is most often generated by powerful emotions such as frustration, disappointment, loss, grief, and fear, and these often possess undercurrents of powerlessness and shame. When we face conflicts with other clinicians, the powerful emotions are the same, but the social contract is different. What do we mean by this? With a patient, the professional relationship allows for emotions to be dealt with; managing emotion is part of a therapeutic relationship. On the other hand, with many professional colleagues, we don't assume that talking about our emotions is part of our professional work. (There are exceptions, but usually we physicians talk about this stuff only with people we really trust.)

In addition, other clinicians – especially those from a different professional discipline – may have concerns about power and respect. Power influences how disagreements or conflicts are presented. A clinician who is higher on the power hierarchy (say, an attending physician) is often treated more gently than a clinician lower on the power hierarchy. Consequently, the clinician with less power (e.g., a nurse) is more likely to be tentative in raising a disagreement, and the clinician with more power (e.g., attending physician) is more likely to miss the fact that the nurse is actually quite upset. The implication is that the higher you are on the power hierarchy, the more carefully you need to be attuned to concerns of other clinicians. If you casually handle an issue important to them, you risk having them feel that their work is not respected.

Thus, when working through a conflict with a colleague, the question ought to be: how do I show that I'm really interested in hearing their views, and what do I need to do to earn enough trust so they tell me? This is the professional equivalent of what we might call "establishing a safe space" with a patient. You need to establish a safe space with your colleague. As with patients, this means that the conversation should be in a

private place, should be out of earshot of patients and other colleagues, and should merit your full attention – all the same principles apply.

The issue of how to address your colleagues' emotions is a bit tricky. While we have advocated attention to emotion, and empathy for patients and family members, our experience is that empathy for colleagues is sometimes misinterpreted as condescending. In particular, clinicians who are higher on the power hierarchy need to be careful about how they address the emotions of their colleagues. Many clinicians implicitly subscribe to a belief that their emotions should not be part of their work and that showing emotion represents weakness. Thus, clinicians need to take care in responding to their colleagues' emotion to frame this in a way acceptable to the colleague. While this takes getting to know the other person, we would venture that with colleagues you don't know well, you may be on safer ground talking about emotions generated by the situation (e.g., "This is really a sad situation") rather than discussing emotion in a way that could be seen as vaguely pejorative (e.g., "You look *really* upset" "You're personally involved with this patient, aren't you?"). As with patients, you may want to name emotion at a step lower than what you are observing (e.g., "I can see this situation bothers you") as a way of acknowledging the emotion in a way that is unlikely to be viewed as pejorative.

ACKNOWLEDGING MY PRICKLY SIDE

I was late, and feeling overworked, and had been in a room with a very demanding family. When I walked out of the room, the nurse intercepted me with a look of reproach. We had discussed trying to make sure the family received a consistent message. The nurse started to talk while I was still 5 feet away, like she didn't think I was going to wait to hear her side of the story. Not hostile – but a little tense. I said, "I do want to acknowledge my role in this. Talking to the family without you was not a good idea. I apologize." To my surprise, she said, "Well, I had not been clear with you either." Acknowledging my contribution quite disarmed her, a bit of repair that got us restarted in a better way.

When a conflict discussion doesn't go well

In dealing with conflicts, we would define a successful conversation as one that results in greater understanding on both sides. Note that this does not mean that the conflict will be resolved, because many conflicts won't be over after one good conversation. Real conflicts occur because people have deep commitments, and thinking about how those commitments translate into actions that resolve a conflict takes time.

If you find yourself just feeling battered after a conversation or feeling like you've been in a brawl, our advice is to first take care of yourself. Give yourself some time to decompress. Ask a colleague you trust to help you think it through. Find a private place to put your own feelings on the table – your frustration, irritation, even sadness. Remember that things that make you upset are probably things to which you are really committed. We also offer a caveat about the way you might typically review what happened. Instead of rehearsing the reasons that you were right, ask yourself if you really understood the other person's thinking. Can you answer the humanizing question about why a well-meaning person is taking this position?

There are some occasions when you should consider an apology. When the other person feels disrespect from you, an apology is in order. Your original intention is not the point here, and you shouldn't mention it. What you should mention is that you are aware that the other person felt disrespected, and that you regret it. When you do apologize, just apologize. Do not use the occasion to try to make your point again. Do not apologize, and end with "but I do think that ..." – it's a mark of insincerity and will make the situation worse.

When people are rude

When patients or colleagues have been rude or uncivil, you may feel quite justified to treat them in the same way they have treated you. It's

human nature. However, being rude in response is likely to escalate the conflict. (Remember: sarcasm is the same as being rude.) For many of us, this requires some serious self-management skill. Again, looking at the emotion as data is helpful – their anger represents frustration or hurt or fear – and figuring this out will help you know what to say next. The measure of your skill is the level of empathy you can bring to the situation.

On the other hand, you are not professionally obliged to be the object of bad behavior. You do, however, need to explain yourself. If a patient or family member is screaming or abusive, it's okay to tell the person in a calm voice, "I realize you feel very strongly about this. I find it hard to talk to you when you are using that kind of language." (Notice that we did not say "But I find it hard …," because the "but" can make the "feeling very strongly" come across as a concession rather than a statement of understanding.) Many people in these situations are unaware of how they are coming across, and if you point this out, they will rein themselves in. (If you feel someone is threatening, however, you should probably stand up, note your concern, leave the room, and call security.)

When the conflict seems unresolvable

If you are having a tough time finding any mutually acceptable options, and the request from the patient, family, or colleague still stands, step back from the situation (and the frustration) for a moment. There are some conflicts that are rooted in different values that better communication will not resolve. For example, a patient and family who feel that life is precious regardless of the quality of the life may butt heads with a doctor who is strongly committed to quality of life. If this family is in conflict with this doctor about continued mechanical ventilation for a patient who all agree is dying of sepsis, it is not likely that a negotiation approach like the

one we described will resolve the conflict – the meaning of ventilation for the family (increased length of life) is too different from the meaning of ventilation for the doctor (unacceptable quality of life).

When the conflict appears to be at a standstill, we suggest you ask yourself 3 reflective questions: (1) How important is this to the other person's core beliefs/values? (2) How important is this to my own core beliefs/values? (3) How flexible can I be in this particular case without compromising an important value of my own? The challenge is to be flexible without compromising your own integrity. Over time, we have found our own responses in these cases to be more flexible, more accepting of what patients feel is really important, and less attached to biomedical outcomes.

There will be times that you find yourself faced with a situation in which you and a patient or family member cannot agree even after discussion and negotiation. If you've followed our approach, the remaining disagreement is likely to be about core values for each of you, and a situation like this can't be solved with better communication skills. In these cases, you need to get help – an ethics consultant, a palliative care consultant, a colleague who can serve as a facilitator, a person in quality management who handles disputes. You may need to agree that the different interests cannot be reconciled in this particular case. In these cases, the communication skill is to disagree gracefully, without backing down from your value but also without describing the other person's value in a pejorative way. For instance, a patient told us what happened when she asked her primary care provider for a prescription to hasten her death. The primary care physician, in response, explained that she could not do that because she would not be able to live with herself afterward. Yet the primary care physician fully acknowledged the patient's terrible situation and legitimacy of the request. This graceful disagreement led to a very clear understanding on the part of the patient and continuation of the relationship. The patient accepted that the physician had very different beliefs about this, but felt understood and heard.

The bottom line

Instead of digging your heels in, look for a nonjudgmental starting point and a shared interest you can articulate.

Maximizing your learning:

1. Conflict is tough because afterward we can feel a bit defensive, beat up, or just bad – and the more you value collaboration, the worse you are likely to feel! Here are some useful follow-up reflective questions (from Stone et al.) that you can use by yourself, or even better, with a trusted colleague.

   What aspects of your identity or self-image might be threatened?
   What might you be denying or exaggerating?
   To what extent are you holding yourself to an impossibly perfect standard?
   How can you regain perspective?
   How can you remember to cut yourself some slack?

FURTHER READINGS

Abbott, K. H. et al., Families looking back: one year after discussion of withdrawal or withholding of life-sustaining support. *Crit Care Med*, 2001, **29**(1): 197–201.

Back, A. L. and R. M. Arnold, Dealing with conflict in caring for the seriously ill: "it was just out of the question." *JAMA*, 2005, **293(**11): 1374–81.

Dugan, D. O., Praying for miracles: practical responses to requests for medically futile treatments in the ICU setting. *HEC Forum*, 1995, **7**(4): 228–42.

Fisher, R., B. M. Patton, and W. L. Ury, *Getting to Yes: Negotiating Agreement Without Giving In*. Houghton Mifflin, 1992.

Kahn, M. C., Understanding and engaging the hostile patient. *Mayo Clin Proc*, **82**(12): 1532–4.

Philip, J. et al., Anger in palliative care: a clinical approach. *Intern Med J*, 2007, **37**(1): 49–55.

Pisetsky, D. S., Doing everything. *Ann Intern Med*, 1998, 128(10): 869–70.

Stone, D., B. Patton, and S. Heen, *Difficult Conversations: How to Discuss What Matters Most*. Penguin Books, New York, 2000.

9 TRANSITIONS TO END-OF-LIFE CARE

Uncovering the big picture amidst fear and failure

What counts as a transition?

When prolonging life together with an acceptable quality of life no longer seems achievable, we are prompted to change the goals of care. Discussing such a change begins a process of transition that, however necessary, is also very scary. The paradigm for transition conversations is drawn from cancer medicine, when patients have no further anticancer options and stop receiving anticancer therapy. For other serious illnesses, the transitions may be more subtle. For a patient with HIV, the transition might be when antiretroviral meds no longer seem worthwhile. For a patient with heart failure, the transition might be when the patient is bouncing between pulmonary edema and renal insufficiency. In any case, talking about transitions is an uncomfortable moment for patients and clinicians alike. For many patients, making a conscious, explicit decision to stop disease-modifying therapy requires giving up hopes for living longer. For physicians, recommending the discontinuation of disease-modifying therapy often feels like failure.

Any failure is usually the result of overwhelming pathology, but physicians can't help but feel that they have been personal failures. This makes talking about disease progression difficult. As one of our Oncotalk fellows put it, "I just don't think I'm good at this. I think it's probably my own personal anxiety." As a doctor, you've helped other patients beat the odds (and taken pride in doing so), so what happened here? The answer (even if unconscious): you must have done something wrong. Or maybe you could have done something a little bit better. Either way, it doesn't feel good, and if the patient doesn't want to stop therapy, the physician is supposed to convince the patient why the treatments to which they had both made a substantial commitment are now, in retrospect, a waste of time and effort. Another Oncotalk fellow told us, "having a patient say 'Now *you're* giving up' makes me feel so terrible – on top of my own feelings of defensiveness – it doesn't feel good not to be offering something else." So, is it any surprise that physicians tend to avoid these conversations and the patients who remind them of their shortcomings?

Because transition conversations are so uncomfortable, clinicians often try to recast this conversation into a discussion about choosing options for care. Yet it's not about choosing options in the usual sense. This is a conversation about options that no one wants to have. No matter how important or appropriate it is to shift the goals of care from extending life to providing comfort, the fact remains that talking about transitions means that the medicine isn't working, and this invokes disappointment, loss, and sadness. These conversations force patients to confront the failure of medical treatments ("why didn't this work for me?"), their own failure ("maybe I should have chosen a different treatment or different doctor?"), and existential and spiritual crises ("why is this happening to me? Didn't I pray hard enough?").

These dynamics make talking about transitions much more complex than giving serious news. Because it is so hard, the most common

approach we see is for physicians to ignore the actual transition and to focus on interventions that might be invoked at the very end of life, such as cardiopulmonary resuscitation (CPR) and mechanical ventilation. Or they maintain that things are "just fine" until they say that "nothing more" can be done. In the next chapter, we'll talk about dealing with CPR. Here, we want to describe an approach to talking about transitions separately from resuscitation because we think this enables patients to make better decisions, adjust to the difficult reality they are facing, and continue trusting their doctors.

THE PITFALL: Keep cheerleading until you decide it's time for the patient to be "realistic."

THE SOLUTION: Work on the big picture and the goals that are still achievable.

The research available on this topic indicates that patients want to negotiate when to talk about dying and that they often want some control over the process. They also harbor painful memories of being told that "there is nothing more to be done," a phrase that should always be avoided.

The strategy of redirecting hope from living longer to looking toward "a good death" is widely known but often used ineffectively. We find that without a substantial understanding of the patient, simply recommending a shift in goals often fails. To your patient, hearing that he should have new goals sounds simplistic and looks expedient. Our experience is that shifting goals is most successful when it evolves from patients' values, and this takes some exploration. Just as reassurance works best only after you have learned the patient's real fears, redirecting goals is most successful when you have a sense of what is really important now and what hopes the patients is giving up. In addition, you need to emphasize that the patient will continue to have access

to your expertise and that you are not simply pushing them off to hospice. You can't change the reality the patient faces. What you can do is to create a conversation that will provide medical expertise, support, and understanding so that in that moment, the patient can think clearly about the changes they are facing.

Key skill: constructing the "big picture" view with the patient and family

The roadmap for discussing transitions:

1. *Prepare yourself*. These conversations are tough, and the more you have been able to think through the case, and come to terms with your own feelings, the better you will be able to hear subtle cues and respond to what is happening in the moment.
2. *Ensure the patient or family understands the medical situation*. Often this discussion represents serious news, so make sure to track and respond to the emotion data (see Chapter 3).
3. *Assess the patient's readiness to talk about what's next?* Patients who are overwhelmed or sad may have a difficult time talking about the next step because they are overwhelmed with emotion – in which case some time and space may be necessary. We judge readiness by the patients' willingness to engage with us in a dialogue, and this does not mean that they have worked through all their shock and grief. (We rarely have the luxury of that much time.) You might ask, "How much have you been thinking about what you would do if things got to this point?"
4. *Use big picture questions to elicit patient values and goals*. The big picture questions we use first focus on what's valuable, what's positive, and what makes life precious for this individual. Try to refrain from commenting on the feasibility of goals or hopes – use this part of the conversation to appreciate and align yourself with the person.

Note that we usually leave questions about legacy until a later conversation – you need to engage the person before asking them to think about a future in which they don't exist.

a. *What is most important to you now?* This question helps draw the big picture by outlining a person's major priorities in life. Another way to ask this would be to say, what are your biggest goals? We've observed that most people are able to talk freely about this question, and it serves well to draw them out. Rarely, someone may respond simply, "I want to live." In this case you can say, "I'm hoping for the same thing for you. Tell me what about your life is most valuable right now and most makes you want to live?"

b. *What are you hoping for?* You may want to preface this question by noting that most people are hoping for many different things and that you like to diversify the portfolio of hopes. If the answer is "curing the disease," acknowledge that hope, then ask, "is there anything else?"

c. *Tell me what is going on in your life outside the clinic or hospital?* This question can help you identify what the patient is trying to do and what they value. In addition, it can help you understand how he is trying to cope and how effectively his coping strategies are working. Make sure you know what the patient enjoys now.

5. *Outline worries that are barriers to decision making.* At times, articulating a worry can free a patient to talk about the goals.

a. *What are your biggest concerns right now?* You may want to be even more specific, and say, "As you think about the future, what concerns you the most?"

b. *What is the hardest part for you? And your family?* We find that many physicians balk at this question because they worry about opening a pandora's box of unsolvable issues. The point

of this question is to enable the patient to articulate what he is up against and the fact that you, his physician, are interested in making the hardest things discussable.

6. *Offer to make a recommendation*. Notice that we ask for permission before the recommendation. "Now that I understand more about your situation, would it be helpful for me to make a recommendation?" The more you can engage the patient, the better he will hear the recommendation. As a physician, your job is to match patients' values and goals with the appropriate treatment options that will help them achieve these goals. This requires listening intently and then giving a recommendation based on what you've heard. Some physicians worry that to do so takes away patient autonomy. We believe that exactly the opposite is true. Patients are looking for a recommendation from their physician, and they have the power to accept or reject this advice. Remember – your recommendation is not based upon what you would want for yourself. Instead, it reflects what patients tell you is important to them. We have made recommendations for treatment that we would never wish for ourselves, because it is clear that, for that patient, very aggressive intervention was consistent with their needs. If a patient or family is not ready for a recommendation, you should reconsider offering one. Are they still thinking about disease status or therapy? Are the goals or values still fuzzy? You might offer: "We know from talking to other patients that there are some things most people worry about." These things are
   - good pain and symptom control – being reasonably comfortable
   - strengthening relationships with loved ones – saying the things you want to make sure you have said
   - relieving burden on family – feeling that your family can manage during your illness
   - achieving a sense of control – feeling that your wishes can be carried out to some degree

- avoiding inappropriate prolongation of dying – not dying on a machine or "like a vegetable."

7. *Propose a new treatment plan that meets the patient's goals*. As mentioned earlier, we suggest that physicians look carefully at the big picture the patient has drawn, use their medical expertise, and propose a care plan that promises to fulfill at least some of the patients' goals and hopes. One of our wiser colleagues calls this "the art of the possible." We think the most successful plans contain some elements that are slam dunks, some that are reasonable targets, and a couple that are aspirational long shots. For example, a plan might include mentioning interventions to achieve good pain control (high probability), consulting a psychologist to improve the kids' adjustment (reasonable probability), and getting the social worker to contact an estranged sibling (long shot).

   By proposing, we mean that physicians take responsibility for the technical issues, and relieve patients of evaluating whether a particular intervention will get them closer to a particular goal. Hospice may be an important part of many of these new treatment plans. Detailing the services that hospice provides is outside the scope of this book, but we will point out that we think it important to talk specifically about what the hospice will do to meet the patients' needs or goals and what the hospice will do better than anyone else. Skip the vague endorsement. But point out how you will still be part of the team.

   The time course for the plan will depend on the clinical situation. For a patient in the intensive care unit, it might cover hours; for a patient with slowly progressive dementia, the plan might stretch over weeks.

8. *Ask for feedback about your proposal*. Some back-and-forth discussion is important to craft a plan to which all agree. Your willingness to modify, rethink, and go back to the drawing board

demonstrates your flexibility and willingness to meet someone where they are.

The following example illustrates some of these points. We are joining this conversation in midstream – after Dr. B has spent time going over the scans, giving the bad news about things not working, and dealing with the sadness. At this point, Dr. B and Ms. T have decided to move on and talk about what is next.

WHAT HAPPENED	WHAT WE CAN LEARN
Dr. B: I think we're coming to a point where we have to sort of change what we're working toward. Because all these things we've tried to do to extend your life haven't worked. But I think there's still a lot we can do to make the quality of life better for the time that you have.	*Assessing patient readiness to talk about end-of-life care.*
Ms. T: [10 seconds silence] Oh. I'm still …	
Dr. B: I know it's hard to get your head around this sort of issue. I think the way to approach this is to think about what's important to you. [3 seconds silence] If we can figure out what's important …	*Acknowledging difficulty of the topic. Suggesting a way into discussing the topic. Giving silence as space to allow the patient to decide if she can talk about this.*
Ms. T: What's important, you're not going to be able to give me, though. What's important to me is watching my son grow up.	
Dr. B: Tell me more …	*Implicitly asking to hear more about this – the patient is outlining the big picture issues.*
Ms. T: Watching my kid play soccer – that's his new thing. Plus, what do I go home and tell my husband? That I'm giving up?	
Dr. B: [3 seconds silence]	*Giving more silence as space to allow her to think.*
Ms. T: I guess I'm pissed.	

WHAT HAPPENED	WHAT WE CAN LEARN
Dr. B: You're maybe angry that this is happening?	*Offering a reflection about the situation.*
Ms. T: Yes. And I don't know where to start.	The patient confirms the anger.
Dr. B: It can sometimes feel overwhelming. I have a couple of ideas about where to start. What do think about this? Let's start with talking to your husband. Then let's focus on your son. And we can work on your quality of life to help you do all that.	*Offering to make a recommendation that addresses her concerns about her husband and son.*
Ms. T: That sounds good.	
Dr. B: You said you were worried about telling your husband you are giving up.	*Revisiting a concern.*
Ms. T: Yeah, he will say that I just need to keep trying. He does not have to live with the side effects. I do not think he understands how hard it is.	
Dr. B: That is hard. Do you want us to talk to him together?	*Proposing a plan – note this is framed as an offer.*
Ms T: No, I want to – but what do I say?	
Dr. B: I can give you some advice if you want.	*Proposing a slightly different plan, again an offer.*
Ms. T: Yes, that would be good.	
Dr. B: Often when people say don't give up, what they are saying is how sad they are that things are not going well. Their sadness and worry about the future makes it hard for them to imagine the future. Just telling him that you know how sad he is that things are not going well may help.	*Giving advice, framed as "what people say" rather than "what your husband thinks" – which Dr. B can't really know.*
Ms. T: Ok.	
Dr. B: And I often point out that the cancer has made this decision, not you. It is not like you do not want to get better. Your spirit and hope and work in for the future is there. Do you think your husband could see this?	
Ms. T: I can try that, I think.	

How patients respond to transitions conversations?

In our experience, patients respond to these conversations in three ways: they accept the clinician's assessment that a transition is occurring; they want to negotiate; or they decline the clinician's assessment.

Patients who accept that a transition is occurring are ready for specific end-of-life planning. We judge that this has happened when patients articulate that they understand, state that they are ready to hear more, and ask questions about what will happen next and what they should be ready to do. These patients are ready for intensive planning and explicit discussions.

Patients who want to negotiate perceive that they are close to a transition, but want to see more evidence. These patients, in our experience, tend to raise questions about the clinician's assessment and want to discuss the assessment with others – including clinicians, family members, friends, or spiritual counselors. For these patients, we recommend that the clinicians engage the patient and family in a discussion of clinical milestones. The most useful milestones are markers of disease progression that the patient and family will recognize as independent of clinician judgment (a CT scan measuring the size of metastatic lesions). The next step is for the clinician to construct a time-limited trial of medical therapy using the milestones to judge success (e.g., another month of chemotherapy followed by a CT scan). We find that this process can enable patients and families to step away from concerns about clinician judgment and commitment ("are they just giving up on me?") and toward a realistic assessment of their situation.

Patients who decline the clinician's assessment that a transition is occurring, in our experience, appear undecided, quizzical, or unengaged. Some withdraw from the conversation, which clinicians

may miss if they assume the patient accepted and move straight into a discussion about end-of-life planning. Many patients who decline will not articulate this directly to the clinician – they do not wish to confront, contradict, or disagree. They tend not to participate in end-of-life planning that follows – for example, they will listen to a discussion about hospice, but when the nurse arrives will decline to sign up.

In our experience, the most common reason that patients decline the clinician's assessment is that they find the prospect of being at a transition too sad, too frightening, or too threatening. This is often labeled as "denial" and, indeed, it may be. But, if they are in denial, it is because accepting the truth is too difficult psychologically. These patients are the ones that tempt clinicians to "confront them with the truth," "hang crepe," and "hit them over the head with it" – mostly because the clinicians are frustrated. In these situations, we find that the most useful communication tool is to pay attention to the emotion data, and ask about it. In a conversation with trusted clinicians who construct safe space, patients may be able to explore, tolerate, and understand emotions that they could not otherwise face. What clinicians do to be successful at this point is probably beyond any particular phrase or approach. The clinicians whom we admire rely on attention to subtle patient cues, highly calibrated self-awareness, and complete authenticity. We often hear clinicians speaking of the need to give patients "more time." While we agree that patients may need more time, we think it is helpful to remember that the time they need is time exploring their feelings – either with us or with another person with the needed skills.

The bottom line

A transition to end-of-life care is a turning point in a life – a big, scary, hairy one. Patients and families may not remember the exact words

you used, but they will remember your respectfulness, attention, and empathy.

Maximizing your learning:

1. Transitions conversations often bring up feelings of helplessness, being out of control, and grief for things lost. These powerful emotions are uncomfortable to be with for a clinician, but your willingness to allow these to be present gives a very powerful signal that you are able to talk with the patient about what's really important and can be present with the emotion – which is therapeutic in itself. Think back to an emotionally powerful conversation you had with a patient about a transition. What were the feelings that you can remember? (We often find many feelings rising and falling through the course of an important conversation.) Which feelings could you hold easily? Which feelings were tough – that perhaps you really wanted to get away from, or fix or, stop? Identifying these difficult-to-be-with feelings can tell you where your learning edge is located around transitions. Don't forget to notice, however, the feelings that you could hold – what happened to those as you held them?

FURTHER READINGS

Meier, D. E., A. L. Back, and R. S. Morrison, The inner life of physicians and care of the seriously ill. *JAMA*, 2001, **286**(23): 3007–14.

Pollak, K. I. et al., Oncologist communication about emotion during visits with patients with advanced cancer. *J Clin Oncol*, 2007, **25**(36): 5748–52.

Quill, T. E., R. M. Arnold, and F. Platt, "I wish things were different": expressing wishes in response to loss, futility, and unrealistic hopes. *Ann Intern Med*, 2001, **135**(7): 551–5.

Rabinowitz, T. and R. Peirson, "Nothing is wrong, doctor": understanding and managing denial in patients with cancer. *Cancer Invest*, **24**(1): 68–76.

Reinke, L. F, R. A. Engelberg, S. E. Shannon, M. D. Wenrich, E. K. Vig, A. L. Back, and J. R. Curtis, Transitions regarding palliative and end-of-life care in sever chronic obstructive pulmonary disease or advanced cancer: themes identified by patients, families, and clinicians. *J Palliat Med*, 2008, **11**(4): 601–9.

Schofield, P. et al., 'Would you like to talk about your future treatment options'? Discussing the transition from curative cancer treatment to palliative care. *Palliat Med*, 2006, **20**(4): 397–406.

10 TALKING ABOUT DYING

"Do not resuscitate" orders and goodbyes

How you talk about dying makes a difference

Talking about dying can be one of the most frustrating communication tasks or, paradoxically, one of the most satisfying. The reasons for frustration are formidable: patients are "not ready," "in denial," or "unrealistic." The reasons for deep satisfaction are equally impressive, in a different way. Physicians describe the experience of talking to dying patients as a "privilege," "life-changing," or "amazing." What accounts for the divergence? Certainly, patients vary considerably in their willingness and capacity to talk about their own impending death. In addition, different cultures have different ways of talking about death. Yet, in our experience, the most powerful variable surrounding discussions of dying has to do with the physician rather than the patient. If you practice the roadmaps in this chapter, you could change your experience of talking about dying from chronically frustrating to commonly rewarding.

Why is talking about dying so tricky?

The two communication tasks in this chapter might be the most difficult, but for completely different reasons. While most physicians have lots of experience talking about resuscitation preferences (commonly called "talking about cardiopulmonary resuscitation [CPR]" or "do not resuscitate [DNR] orders") with patients, many have never seen the roadmap we recommend. Furthermore, when it comes to saying goodbye to patients who are dying, many physicians have no experience at all. Certainly there is more to say about dying than we can cover in this chapter. But these two moments – talking about resuscitation preferences and saying goodbye – represent touchstones in a patient–physician relationship.

Don't use DNR orders to introduce dying

It may seem easier to wait until you are forced to talk about dying, either because the patient's body is failing, or because a nurse prompts you to write a DNR order. But the downside of this procrastination strategy is that the patient and family must change direction in one conversation, and for many patients, it is too much. These patients have seen their physicians as reassuring cheerleaders until one fateful day when the physician turns, as one family member put it "completely negative." This is the reason that in this book we have intentionally split the transition conversation from the "No-CPR" conversation. Most patients and families need time to understand and adapt to the changing reality of approaching death. Their tasks go far beyond understanding the medical situation, and often, they cannot make decisions about resuscitation until they have come to terms with own mortality to some degree.

The pitfall physicians fall into is to talk strictly about the medical interventions. "Do you want us to do chest compressions?" "Give

pressors?" "Intubate?" This entire strategy may be an unintended consequence of ethical guidelines that stress the importance of talking about resuscitation at the end of life – many physicians think of this as "going in to get the DNR order" – in which patient autonomy and choice are made paramount. However, near death most patients feel terribly vulnerable, have a strong sense of their dependence on medical technology (it kept them alive thus far), and fear being abandoned by their physicians. Thus, our cognitive roadmap for DNR orders has you guide the patient by helping them build the "big picture" – what does the patient consider important if time is limited? – and then, making a recommendation about what should (and should not) be done based on these values. Once you've articulated what you will do to care for the patient, only then you do make a recommendation about CPR.

THE PITFALL: asking separately about every part of resuscitation.

THE SOLUTION: guide the patient by developing the big picture, talking about the care plan, and making a recommendation about CPR.

Bucking a "death-denying" culture?

Performing CPR on a dying patient feels to many physicians like an assault – it violates their notion of a good death. However, many patients and families have little first-hand experience with the process of dying. They've seen CPR work on television (where the resuscitated patient lives for another episode more than two-thirds of the time); they've seen the ads from your medical center promising miracles with the newest technology; they know about Lance Armstrong's battle with cancer that resulted in winning the Tour de France seven times. Your patients live in a culture that Kathleen Foley called "death-denying," and to them, when you talk about forgoing resuscitation for a better death, you look like the outlier.

We have great sympathy for physicians who have been fired by patients because they talked too much about dying, because we've been there. The problem physicians can get into is that, because of their clinical experience, they are often thinking several steps ahead of the patient and family. Talking about dying requires the patient and family be willing and able to think about the medical treatment not working. Elisabeth Kubler-Ross talked about the "stages" of adjusting to death – denial, bargaining, anger, grief, and acceptance – and while patients do not necessarily follow this exact sequence, this work reminds us that this acknowledgment is a process. And if they have not acknowledged the possibility of death, then it is very unlikely that they will consider not performing a "life saving" treatment like CPR.

The mark of an accomplished communicator here is to create a conversation (or series of conversations) in which the patient and family absorb the information and gradually create their own vision of the future. You need to guide patients and families to a deeper realization of the medical situation at a speed that they can cognitively and emotionally tolerate.

It is also important to put your values aside and help the patient and family come to their own view of what, given the medical reality, is best for them. This means allowing them to make decisions that might be different than those you would make for yourself. For example, knowing that artificial hydration and nutrition do not prolong life in advanced cancer, you might think that these therapies "make no sense for a man with esophageal cancer who cannot swallow." However, as you talk to the couple, his wife talks about "fixing dinner" for him by hanging his hydration for the day and describing it as "chicken florentine" or one of his other favorites. Her knowing smile while she relates this made their life at home a little more visible and made his commitment to her suddenly real. Given this understanding of why these treatments have symbolic value, you are better able to help them make decisions that promote *their* quality of life.

Working in the shadow of death

In our workshops, one of the most powerful insights that physicians unearth is that they hesitate to bring up dying because they know that the discussion will result in strong emotions, from the patient, the family, and themselves, and they're not sure what to do with all that emotion. So they hesitate to bring up the fact that the patient is dying, and their hesitation to talk about death, frankly serves as an unintended model for how the patient and family should deal with dying – avoid it. The kind of professional development that needs to happen here goes beyond a communication skill. What these physicians need is to develop more capacity to be in the presence of their own strong emotions and those of their patients. (You can learn it, although most medical training doesn't address it.) The complicated thing is that these physicians don't always recognize that they are avoiding the emotion. Their learned avoidance happens so fast that they are unaware of it. But what they do notice is that they get stuck with patients and families again and again. We will have more to say about how to develop this capacity, a personal sort of emotional intelligence, in the next chapter. But here we want to say that developing your capacity for emotion is a long-term project, and in the short term, it can help to have another person who can help you deal with the emotion with you – a nurse, a social worker, a palliative care consultant.

THE PITFALL: hesitating to bring up death because the emotion will be too much.

THE SOLUTION: find a colleague to sit with you in the visit, and expand your own capacity to deal with emotion.

Roadmap for discussing resuscitation preferences (DNR discussions)

This roadmap is based on understanding the patient's perceptions and goals and then making a recommendation about care that includes

consideration of CPR. At first, it may seem indirect. But remember this conversation is not about offering all possible interventions in a value neutral way; you need to align your recommendations with the patient's values.

1. *Decide why you need to discuss a DNR order*. Think about your own rationale. There are two types of DNR conversations. One is the quick check-in during a workup, which we consider part of the review of systems ("Do you have a living will or something like that?"). This is a yes/no question – not the discussion we are talking about here. In this map, we are talking about a discussion aimed at coming to a medical decision about future care. Note that this extensive kind of DNR conversation is not a substitute for a transition conversation that usually needs to happen first. Remember that trust is at stake. You want to be transparent about your rationale for discussing DNR now and why it is worth spending a bit of time talking about the worst case scenario. Otherwise, patients will wonder whether you are trying to tell them something they don't know. (You're not, you're trying to plan for the worst case scenario.)
2. *Elicit the patient's perception of illness and patient values for care*. Here we find questions that point patients toward a values discussion like "What are you concerned about?" and "What is most important to you if time turns out to be limited?" to be most useful.
3. *Discuss the "big picture" of what's happening medically*. By "big picture," we mean a global view of the situation – very often clinicians focus on individual test results and do not bring them into context and meaning for the patient and family. You may need to provide information about the seriousness of the situation if the patient's or family's perceptions are not accurate.
4. *Make a recommendation about DNR as part of the care plan*. Discuss medical priorities and a care plan that will address those priorities.

Discuss things you are doing first. Make a recommendation about DNR as the last part of the care plan. *Explicitly* link your recommendation to the patient's values and perceptions elicited earlier, and ask what they think. It is not necessary to ask for permission for each intervention. If you must cover specific interventions (e.g., a requirement in New York state), you can simply describe what your recommendation covers in enough detail to fill out the required form.

5. *Respond to emotion*. Patients and families often recognize that this represents a milestone in the illness, and they're right. Be prepared for emotions like fear, grief, and sadness. Anticipate worries about dying, and the possible need for a discussion about this.
6. *Tell the patient that you will document the conversation and write an order*. Explain that the order can be changed at any time. Remind the patient and family that medical care will continue, as patients are worried about being abandoned. If you are dealing with hospice, you may want to emphasize how you work with hospice.

Example discussion

Here's part of a conversation between a patient with advanced cancer who has been receiving chemotherapy and has been hospitalized for pneumonia – we're picking up the conversation midstream.

WHAT HAPPENED	WHAT WE CAN LEARN
Dr. A: I'm glad to see that your pneumonia seems to be stabilizing. Could we change topics now and talk for a few minutes about the overall care plan? There are some recommendations I would like to make, and get your feedback about.	*Using signposting to denote topic change. Framing recommendations as asking patient for feedback.*
Ms. C: Ok.	

WHAT HAPPENED	WHAT WE CAN LEARN
Dr. A: I am hoping that we have turned the corner on this pneumonia and that you will continue to improve. That's the best case scenario, and I will do everything possible to make that happen.	*Giving the big picture of the medical situation.*
Ms. C: Thank you, that is what I am hoping for too.	
Dr. A: I would also like to be prepared for the possibility that things do not go the way we hoped. I know this can be tough to talk about.	*Giving rationale for talking about dying that involves the doctor (not the patient) – I want to be prepared – and acknowledging difficulty. Note that "Hope for the best, prepare for the worst" is implicit in this comment.*
Ms. C: I *would* like to be prepared …	
Dr. A: What are the things that come to your mind when you say you want to be prepared?	*Eliciting patient concerns.*
Ms. C: Well, I want my husband to be able to accept this, he is having a hard time.	
Dr. A: That's important. Is there anything else?	
Ms. C: Umm, I would like to talk to my daughter and son but I'm not sure what to say.	
Dr. A: Also very important. How much have you been thinking about dying?	*Asking explicitly about dying as he has only alluded to this previously.*
Ms. C: A bit. Of course I know it will happen to all of us.	
Dr. A: That's true. What would you like your dying to be like?	*Asking for patient wishes.*
Ms. C: I would like it to be peaceful, and comfortable. I'd like to be at home.	

WHAT HAPPENED	WHAT WE CAN LEARN
Dr. A: Those are very helpful things for me to know, because I can do a much better job for you. Based on what you have told me, could I make some recommendations now?	*Reinforcing rationale for to talk with patient about dying. Asking permission to make recommendations.*
Ms. C: Yes.	
Dr. A: Remember we just talked about the best case scenario for what is happening now? I'd like to talk about the worst case scenario, too. If this pneumonia got worse, we would likely consider moving you to the intensive care unit and even putting you on a breathing machine. But the risk of doing that is that you could end up dying in the ICU, which is not really the most peaceful place. If you would like to be at home, and have as peaceful a death as possible, I would recommend that if things got worse that we should try to have you go home with hospice, so that you could spend as much time at home as possible. Does that make sense to you?	*Making a recommendation about the worst case scenario.*
Ms. C: Yes it does.	
Dr. A: I would also recommend that we focus on your comfort at the time of death, and not do CPR. I don't think CPR would really help you have a peaceful death at home. What do you think about that?	
Ms. C: I thought CPR could bring me back.	
Dr. A: Well, it does look like that on TV. But in reality, if the cancer is the problem, CPR doesn't change the cancer.	
Ms. C: I see what you mean.	

This is only a brief excerpt from this conversation, and we would expect that this doctor and patient might continue to talk about the issue, and might circle around again through the issues. However, we think that keeping the focus on the big picture, and using an implicit "Hope for the best, prepare for the worst" philosophy are useful underlying principles for these discussions.

Saying goodbye to patients who you do not expect to see again

Remember the patient you saw for one last time in the hospital before discharging him to hospice. Did you say goodbye or acknowledge that this was likely the last time you would see him? Many physicians avoid these goodbyes. The problem is that leaving without saying something can leave patients and families feeling like you've abandoned them.

Physicians give a variety of reasons for avoiding goodbyes. We say we are concerned about the impact on patients or families: acknowledging we will not see patients again makes it clear that they are dying and will make them too sad. We may worry that patients will feel abandoned or that we are giving up on them. Another barrier involves prognostic uncertainty: we cannot be sure that the patient will not be readmitted next week, which could result in an awkward encounter. There also are emotional barriers. It is hard to say goodbye, and many physicians worry that they will get emotional and that showing our own emotions is unprofessional. Finally, these personal reactions reflect embedded cultural values about dealing with loss and the role of medicine. Biomedicine emphasizes cures, and neither physicians nor their patients like to be reminded that medicine is frequently less than curative. For all these reasons, we often discharge patients without ever acknowledging the sadness and loss running just beneath the small talk.

By ignoring the end of the relationship, clinicians miss an important opportunity because a goodbye can have a powerful positive effect. By saying goodbye, we both acknowledge the end of the relationship and at the same time underscore its importance, leaving the patient with a sense of feeling valued and cared for rather than abandoned. Saying goodbye also gives the patient an opportunity to say thank you and to look back over the course of a relationship. For physicians – especially those in training – a goodbye can be an opportunity to tell patients how they have contributed to that physician's learning and how it will help other patients in the future.

How might one go about saying goodbye? These steps will help:

1. *Choose an appropriate time and place*. A setting that affords some privacy will make it easier to be personal. The end of the visit may seem like a natural time to say goodbye, but we note that a physician who has had a long, rich relationship with a patient should plan enough time so that there is time for a correspondingly rich and meaningful goodbye.
2. *Acknowledge the end of your routine contact*. This acknowledges that you will not be making future appointments, and sets the stage for a conversation about closure.
3. *Invite the patient to respond, and use that response as a piece of data about the patient's state of mind*. Saying "Would that be ok?" or "How would you feel about that?" enables patients to have a bit of control over the conversation, and allows them to gather their thoughts. It also enables doctors to assess patients' willingness to talk about the topic and their emotional frame of mind.
4. *Frame the goodbye as an appreciation*. We think doctors can use a goodbye opportunity most powerfully by citing something that you truly appreciated about that patient, something that would give him a sense of that you knew him as more than a diagnosis. Some

examples: "I just wanted to say how much I've enjoyed you and how much I've appreciated your flexibility (or cooperation, good spirits, courage, honesty, directness, collaboration) and your good humor (or your insights, thoughtfulness, love for your family)." If it seems appropriate, the physician can acknowledge the loss of the relationship: "I'll miss not seeing you in clinic and hearing about your grandchildren and your husband."

5. *Give space for the patient to reciprocate*, and respond empathically to the patient's emotion. Acknowledging loss and death can make even well-adjusted, high-functioning patients (and physicians) anxious, and this might be something to acknowledge: "I realize this might seem awkward, but I wanted to make sure that you knew how I felt, rather than risk not having the chance to tell you."

   In our experience, patients often talk about how much they appreciate the doctor's time, effort, and concern. These positive statements may be particularly hard for physicians who may be feeling guilty that their medicines could not do more for the patient. If patients do express appreciation, it is important to receive their comments without minimizing them. Say "thank you" rather than "it was nothing, the nurses did it all." The patient is giving you a gift, and it is important that you receive and appreciate it. Not doing so may leave that person feeling unheard.
6. *Articulate an ongoing commitment to the patient's care*, to make it clear the patient is not being abandoned. Consider saying something like, "Of course you know I remain available to you and that you can still call me. Your hospice nurse will keep me informed about what is happening. I will be here if you need me, and I'll be thinking about you."
7. *Later, reflect on your work with this particular patient*. Many physicians received training as house staff that created the expectation

that deaths are not discussed much, that physicians cope by being silent and strong, and that avoiding talk about death is part of self-preservation. We observe that many physicians have involuntary ticker-tape responses that reflect beliefs that may not serve their professional work and personal growth, and that developing a conscious awareness of these beliefs is an important tool. It may be worth asking oneself: What do I want to take away from my work with this patient? Because the meanings that physicians assign to their work shape their professional identities, they are worth a measure of mindful attention.

Example conversation

Again, we pick up a conversation midway.

WHAT HAPPENED	WHAT WE CAN LEARN
Dr. A: So I think we've covered everything for today. I will ask the hospice to call you tomorrow, and if you don't hear from them, please call us.	*Finishing the medical business before starting a goodbye.*
Mr. G: Ok.	
Dr. A: There is one more thing.	
Mr. G: What's that?	
Dr. A: I will make an appointment for you to come back in 2 to 3 weeks, to see how you are doing. If it is too much work to come in, you can just call us. So if I don't see you in person again, I want to make sure you know that I've enjoyed working with you. I've admired your spirit. Thank you.	*Acknowledging that future contact is uncertain but possible. Framing goodbye as an appreciation.*

WHAT HAPPENED	WHAT WE CAN LEARN
Mr. G: Well … thank you too. I don't think I would have had this much time without you. And I have felt well cared for.	*Giving space for the patient to reciprocate.*
Dr. A: You are welcome. That means a lot to me. Now, remember, I will still be available if you need me, I'm just a phone call away.	*Responding to the patient's appreciation. Articulating an ongoing commitment to the patient's care.*
Mr. G: I am thankful for that.	
Dr. A: You take care, now.	

Not every relationship with a patient who is near death affords an opportunity for saying goodbye. Physicians need to have established a level of mutual understanding with their patients about the severity of the illness and have some confidence in their ability to deal with sadness, loss, and grief. Acknowledging the end and saying goodbye is best suited for patients who would welcome a moment of feeling connected to their physician. These conversations may not always be smooth or predictable but they can nonetheless be deeply meaningful. Note that others have written about condolence letters and attending funerals, and while we think these practices can be tremendous for both families and clinicians, they're not communication practices in the same sense as we are focused on in this book.

The bottom line

Conducting discussions about resuscitation preferences is a survival skill for doctors who deal with life-threatening illness. Saying goodbye is an advanced skill for talking to patients to whom you feel particularly connected that can be tremendously rewarding.

THE POWER OF GOODBYE – EVEN WHEN THE PATIENT ISN'T DYING

Last year I decided to focus my clinical practice on palliative care, which meant closing my HIV practice. I was saying goodbye to a woman with HIV who I cared for over 12 years. When we first met, she was addicted to street drugs and weighed 95 lbs. I told her how much she has taught me about second chances and turning one's life around. Then, she surprised me by telling me how much my support meant to her. When faced with something difficult, she would imagine me and what I would say – a way of using my support even when I wasn't there. I had no idea that I played such a big role in her recovery. The memory of her words has gotten me through some difficult conversations, when I wonder how much of impact I really have.

Maximizing your learning:

1. For the no-CPR skills, this roadmap involves a paradigm shift in how to conduct the conversation for clinicians who have only seen the other method. If you have not seen this approach used before, it may be worth watching someone else model this roadmap. When you do watch, take notes. Make two columns on your piece of paper, and on the left put "What they said," and on the right, put "What I noticed" (about facial expressions, where they looked, what the patient's emotions felt like, what my emotions felt like). Then identify one thing you want to try.
2. For the goodbye skills, part of the issue is being ready and anticipating when this might come up. So you may want to commit to looking over your clinic schedule or rounding schedule with this in mind and deciding simply to offer an appreciation – even if it's not in the context of saying goodbye. You may find the act of appreciating a patient or family powerful in its own right.

FURTHER READINGS

Back, A. L. et al., On saying goodbye: acknowledging the end of the patient–physician relationship with patients who are near death. *Ann Intern Med*, 2005, 142(8): **682**–5.

Block, S. D., Perspectives on care at the close of life. Psychological considerations, growth, and transcendence at the end of life: the art of the possible. *JAMA*, 2001, **285**(22): 2898–905.

Casarett, D. J. and T. E. Quill, "I'm not ready for hospice": strategies for timely and effective hospice discussions. *Ann Intern Med*, 2007, **146**(6): 443–9.

Maciejewski, P. K. et al., An empirical examination of the stage theory of grief. *JAMA*, 2007, **297**(7): 716–23.

Prigerson, H. G. and S. C. Jacobs, Perspectives on care at the close of life. Caring for bereaved patients:"all the doctors just suddenly go." *JAMA*, 2001, **286**(11): 1369–76.

Quill, T. E. and C. K. Cassel, Nonabandonment: a central obligation for physicians. *Ann Intern Med*, 1995, **122**(5): 368–74.

Shanafelt, T., A. Adjei, and F. L. Meyskens, When your favorite patient relapses: physician grief and well-being in the practice of oncology. *J Clin Oncol*, 2003, **21**(13): 2616–9.

Tomlinson, T. and H. Brody, Ethics and communication in do-not-resuscitate orders. *N Engl J Med*, 1988, **318**(1): 43–6.

von Gunten, C. F., Discussing do-not-resuscitate status. *J Clin Onco*l, 2003, **21**(9 Suppl): 20s–5s.

11 CULTIVATING YOUR SKILLS

Beyond the roadmaps

In this book, we've used a strategy for improving your communication that is based on a series of roadmaps for critical communication tasks. Our strategy emphasizes the process of communication, and the back-and-forth interaction that results in the best mutual understanding between patient and physician. If you have read this far, you must be seriously motivated to do better. And so in this chapter, we want to let you in on a couple of secrets that will make you more successful as a learner and communicator.

Draw on your stories: what makes your work rewarding?

Being a physician who deals with serious illness is hard enough that everyone who stays in it has some very personal reasons. These reasons, we find, usually take the form of stories – a story about how you made a difference, about what you found rewarding, about the change you wanted to make in the world. Every day, you are writing these stories, and

within them, you can find a way to remind yourself about what part of yourself you want to bring forward. Last week, Tony saw a young woman with metastatic colon cancer who is 47, about the same age as my mother when she died of myelodysplasia. My patient often tells me about her children, and for me, talking to her reminds me that part of my work is a legacy to my own mother. I think of my mother when I'm with this patient to inform the kind of listening I should practice. I'm not listening to say, "Hey I turned out ok, don't worry so much." In fact, I haven't told her about my mother. But remembering my story reminds me why I'm here.

Communication takes on real depth when it comes from a place of deep intention. Rachel Remen observed that physicians who are attuned to their own stories can be surprised and moved. This possibility is one of the things that keeps our curiosity alive – and communication technique cannot make up for the absence of an intention that animates your work. We have seen physicians who try to use empathy techniques when they don't actually feel much empathy; it's rarely convincing enough to work in really difficult situations.

Expect plateaus and bad days

In Chapter 1, we described some learning habits that will set you up for success (see reminder box on the next page). If you have tried out any of the "maximizing your learning" suggestions at the end of the chapters, you will be familiar with picking just one skill at a time to learn, the value of practice, and the importance of feedback. What we haven't said yet is that improvement does not feel continuous. Somehow the process of medical education has left many of us with the assumption that learning is a continuous upward spiral of knowledge and glory. But remember in Chapter 2 that we compared learning communication to learning to ski? Even when the new ways are better, they seem awkward for a while. In fact as you try to use your new skills, you may find your communication

feeling a bit more awkward. Unlearning old habits takes some attention, and energy. Progress in communication skills feels nonlinear, with some backsteps, sidesteps, and rough patches – but your patients will tell you as you're improving.

LEARNING HABITS THAT SET UP YOU FOR SUCCESS

- Record yourself.
- Practice one new skill at a time.
- Ask for feedback.
- Do your own private debriefing.
- Be patient with yourself.
- Pay attention when someone tells you that you did a good job.

Be kind to yourself when you're having a bad day. When you are stressed or tired, you will forget to practice, and you'll revert to your old habits. Not a problem: this is normal. Leave behind the self-recrimination, the catastrophizing thoughts ("I'll never get this!"), the "poor-me this-is-so-hard!" Just get back to your practice. If you are motivated, you can improve – and you'll get to where you use your skills instinctively. You'll gain more confidence, you'll improvise and riff, and you'll own it. Other people will think you were born this way.

Despite your skills, you may still run into the "patient from hell." We've all met someone who made us a little crazy. For example, one of us was once asked what to say to a patient who insisted on having his body sent into outer space as a kind of treatment. We did not have a good answer for this problem. Take a deep breath, and remember that no one is perfect.

Notice where you get stuck and what you avoid

The patient from hell may blast you into outer space once in a while, but when you're seeing lots of patients from hell, you ought to wonder if

you've found a place where you're getting stuck. Like most physicians, we don't like dwelling on our failures, and there is a good reason: clinical training often treats error with shame – so you were not only told you prescribed the wrong medicine, you were humiliated too. Physicians commonly handle the shame in two ways: blame someone (or something) else, or ignore the problem. Both ways get physicians stuck in dead ends. We want you to think about these situations differently – there are places where you can improve. The key is to think about the common feature in these situations that is not working and what you might be able to do differently.

In our teaching, one of the most common stuck points is when physicians know what they ought to say but have trouble actually speaking the words. For example, one of us was consulting on a 65-year-old man, dying of multisystem organ failure in the ICU. Before the family conference, the ICU attending told the team that the "right thing to do" was to focus on comfort because the patient was "dying." But during the conference, the same attending told the patient's daughter and grandchildren that he was "very sick," that his ICU stay "might not go well," that the ICU team was "very worried" – but did not say he was dying. Consequently, the family asked the team to keep "trying everything." After the meeting, we debriefed the attending. The attending said, in a soft voice, "It's just so sad. They wanted so badly for him to get better." This kind of physician sadness – that prevented the physician from articulating a difficult truth – is something we've seen before (and have experienced ourselves). It's the most common place we see physicians get stuck. Our own emotions turn up like popup ads on Web sites, blocking the real message.

Work on your emotional intelligence

Becoming unstuck often requires that we work on our own emotional and social intelligence. Emotional intelligence enables us to detect our

own emotions in real time and manage them. Otherwise, our emotions tend to leak into our speech. Notice, for example, the frustration (or even anger) you glimpse when a physician says "As I have told you before." Social intelligence enables us to use our own emotions to cultivate a therapeutic patient–physician relationship. For example, a patient's hopelessness that makes you feel hopeless could turn into a moment of shared futility – or moment of companionship.

Medical training does not focus on improving your emotional intelligence. In fact, with regard to this skill set, it's more like "sink or swim." While our medical training rewarded biomedical knowledge and objectivity, emotional intelligence was labeled as "touchy–feely," and emotions were treated as irritants that "got in the way" of being objective. What we learned in training was that emotions were messy liabilities. What we have learned since then is that emotional intelligence, once acquired, gives us a whole other realm of data that we use to understand and interact with other people. Missing out on emotional intelligence is like not learning the multiplication tables: you can get by without it, but some things – like communication – are going to be really hard.

Developing communication skills will prompt you to work on your emotional intelligence, so as you improve; expect to be challenged in this domain. We want to warn you to expect this challenge. Developing the capacity to read your own emotions and then deal with them is beyond the scope of this book. But we can say this: it's worth every minute of time you invest. We've spent a lot of time figuring out how we're feeling after a tough conversation, how our own emotions influence what we say (and don't say), and how we can use our own emotions in a positive, healing way. We've sought out colleagues we trust, we've found good therapists, and we've gotten lots of feedback from people (clinicians, patients, and our families) whose judgment we trust. What we realize now is that the physicians we really admire, who are elite communicators, clinicians, and healers, have all done this kind of work – without exception.

What does mastery look like – what are you aiming for?

Once you develop a critical mass of skills, your conversations change in ways that are immediately noticeable to patients – and your colleagues. One Oncotalk fellow e-mailed us days after returning home and using her new skills in clinic. Her first patient looked up at her and said, gratefully, "No one has ever talked to me like this." It was a deeply rewarding moment for that physician, and we know from experience that this can happen to you. These skills stick over the long run because you will get a lot of positive feedback from using them.

The Olympic-level communicators we know have lots of different communication tools, and they know how to use them. Yet, they also have distinctively different styles, reflecting their personalities. Some are funny, others more serious. Yet, like elite pole vaulters using different vaulting styles, they all clear the bar successfully. They are prepared for many different situations and are astute observers of what happens in a clinical encounter. Research on learning shows that experts see situations quite differently from novices. The experts notice different details, have larger and more extensive networks of knowledge, and can use their knowledge and observational power in a specific context. All this rings true for communication.

Furthermore, the most accomplished communicators can make it seem like there are no roadmaps at all. Having read this book, you will be able to identify much of what they do. But these elite communicators go beyond the roadmaps, and this leads us to an important caveat about this book. The roadmaps in this book are a kind of scaffold for learning: they are intended to prop you up until you get your own foundation settled. After a while, you may no longer need them, just as a scaffolding is taken down when the building is finished. Jerome Groopman wrote about finding individual metaphors to use with patients – a beautiful example of how communication can go beyond the roadmaps.

Finally, elite communicators bring something else into their clinical encounters. They have a way of putting every patient at the center of their attention, and a kind of ease with themselves. Whatever you call this quality – Rachel Remen talks about "presence", Carl Rogers labeled it "congruence", Howard Brody calls it a kind of "healer's power "– it is immediately obvious, and probably not something you can learn from reading a book. But we point it out because it remains the hallmark of a clinical encounter in which a physician can bring together biomedical expertise and a refined attentiveness to the whole person.

FEEDBACK THAT CHANGED ME

I had been noticing that I had trouble with patients who frustrate me, but I was not sure why. One day I was rounding with our psychologist when it happened again: the patient started to frustrate me; I tried to be very polite, but she just got angrier. After the encounter, I asked the psychologist what she noticed. She observed that when frustrated, I talked slower in an attempt to be hyper-polite. She hypothesized that the patient felt this was condescending. Now, when I am feeling angry and frustrated, I intentionally pay particular attention to how fast I am speaking and try to maintain a normal conversational rhythm. Patients no longer get angrier!

The bottom line

Expect mastery to feel nonlinear, more like a series of small breakthroughs than a smooth continuous process.

FURTHER READINGS

Balint, M., *The Doctor, His Patient, and the Illness.* Churchill Livingstone, New York, 2000.

Bransford, J., A.L. Brown, and R.R. Cocking, eds., *How People Learn: Brain, Mind, Experience, and School*. National Academy Press, Washington, D.C., 2000.

Goleman, D., *Social Intelligence: The New Science of Human Relationships*. Bantam Books, New York, 2007.

Groopman, J., *The Measure of Our Days: A Spiritual Exploration of Illness*. Penguin, 1998.

Hunter, K., *Doctors' Stories: The Narrative Structure of Medical Knowledge*. Princeton University Press, Princeton, 1993.

Leiter, M. P. and C. Maslach *Banishing Burnout: Six Strategies for Improving Your Relationship with Work*. Jossey-Bass, San Francisco, 2005.

Platt, F. W. and G. H. Gordon, *Field Guide to the Difficult Patient Interview*. Field Guide Series. Lippincott Williams & Wilkins, Philadelphia, 2004.

Silverman, J., S. M. Kurtz, and J. Draper, *Skills for Communicating with Patients*. Radcliffe Medical Press, Oxford, 2005.

APPENDIX A

THE ROADMAPS IN OUTLINE FORM

(so you don't have to search through the book)

CHAPTER 1: TAKING YOUR SKILLS TO THE NEXT LEVEL (OUR BASIC PRINCIPLES)

1. Start with the patient's agenda.
2. Track both the emotion and the cognitive data you get from the patient.
3. Stay with the patient and move the conversation forward one step at a time.
4. Articulate empathy explicitly.
5. Talk about what you can do before you talk about what you can't do.
6. Start with big-picture goals before talking about specific medical interventions.
7. Spend at least a moment giving the patient your complete, undivided attention on your computer and show him you are listening.

CHAPTER 2: GETTING A GOOD START

1. Make a welcoming statement.
2. Ask about the patient's main concerns for the visit.

3. Explain your agenda for the visit.
4. If the patient has more concerns than you think you can address in the amount of time you have, ask the patient to prioritize them.
5. Propose an agenda for the visit.
6. Ask the patient for feedback about the agenda.

CHAPTER 3: TALKING ABOUT SERIOUS NEWS

1. Prepare for the conversation.
2. Assess the patient's perception.
3. Ask for permission to talk about the news.
4. Disclose the news straightforwardly.
5. Respond to the patient's emotion.
6. Summarize the plan.

"Responding to emotions with words (NURSE)"

Name the emotion ("It sounds like this has been frustrating")
Understand the emotion "("It must be hard to be in pain like that")
Respect (praise) the patient ("I'm so impressed that you have…")
Support the patient ("I will still be here, with my team, to help with")
Explore the emotion ("Tell me more about this…")

CHAPTER 4: DISCUSSING EVIDENCE FOR MAKING TREATMENT DECISIONS

1. Prepare for the visit.
2. Frame the decision to be made.
3. Ask about decision-making preferences explicitly.
4. For patients who want shared decision making or patient-led decision making, outline the options.
5. For patients who prefer physician-led decision making, make a recommendation.

6. Check for patient understanding.
7. Establish how the patient wants to proceed with the decision-making process.

CHAPTER 5: DISCUSSING PROGNOSIS

The opening question

1. How much do you want to know?

For patients who want explicit information

1. Negotiate the content of the discussion.
2. Provide the information.
3. Acknowledge the patient's and family's reaction to the news explicitly.
4. Check for understanding.

For patients who don't want explicit information

1. Try to understand why the patient doesn't want to know.
2. Acknowledge the patient's concerns.
3. Ask for permission to revisit the topic.
4. Make a private assessment about whether prognosis might change patient's current decision making.

For patients who are ambivalent

1. Name the ambivalence.
2. Explore the pros and cons of knowing and not knowing.
3. Acknowledge the difficulty of the patient's situation.
4. Consider outlining the options for discussion and consequences.

CHAPTER 6: BETWEEN THE BIG EVENTS

1. Ask the patient about their perspective on a symptom or concern.
2. Empathize with the emotional content of the issue.

3. Offer your clinical experience as a way of creating new possibilities.
4. Follow-up by asking the patient what he is taking away.

CHAPTER 7: CONDUCTING A FAMILY CONFERENCE

1. Prepare the people and the messages for the conference.
2. Introduce all participants and the purpose of the conference.
3. Assess what the family knows and expects.
4. Describe the clinical situation.
5. Ask each member of the family for concerns.
6. Explore the patient's values and how they should influence decision making.
7. Propose goals for the patient's care, and be prepared to negotiate.
8. Provide a concrete follow-up plan.

CHAPTER 8: DEALING WITH CONFLICTS

1. Notice there is a disagreement.
2. Find a nonjudgmental starting point.
3. Listen to and acknowledge the other person's story/concern/viewpoint.
4. Identify what the conflict is about, and try to articulate it as a shared interest.
5. Brainstorm options that address the shared concern.
6. Look for options that recognize the interests of everyone involved.
7. Remember that not every conflict can be resolved.

CHAPTER 9: TRANSITIONS TO END-OF-LIFE CARE

1. Prepare yourself.
2. Ensure the patient or family understands the medical situation.

3. Assess the patient's readiness to talk about what's next?
4. Use big picture questions to elicit patient values and goals.
   a. What is most important to you now?
   b. What are you hoping for?
   c. What do you enjoy doing now?
5. Outline worries that are barriers to decision making
   a. What are your biggest concerns right now?
   b. What is the hardest part for you? And your family?
6. Offer to make a recommendation.
7. Propose a new treatment plan that meets the patient's goals.

CHAPTER 10: TALKING ABOUT DYING

Talking about Discussing resuscitation preferences

1. Decide why you need to discuss a "do not resuscitate" order.
2. Elicit the patient's perception of illness and patient values for care.
3. Discuss the "big picture" of what's happening medically.
4. Make a recommendation about DNR as part of the care plan.
5. Respond to emotion.
6. Tell the patient you will document the conversation and write an order.

Saying goodbye

1. Choose an appropriate time and place.
2. Acknowledge the end of your routine contact.
3. Invite the patient to respond, and use that response as a piece of data about the patient's state of mind.
4. Frame the goodbye as an appreciation.
5. Give space for the patient to reciprocate.
6. Articulate an ongoing commitment to the patient's care.
7. Later, reflect on your work with this particular patient.

APPENDIX B

ACKNOWLEDGMENTS

We started working together 10 years ago with the first Oncotalk grant. We have learned an immense amount from each other and in this collaboration we've done things none of us could have achieved alone. We hope the book contains some of the excitement and pleasure that we have experienced together.

We're grateful to our collaborators on Oncotalk, Walter Baile and Kelly Fryer-Edwards, who have sharpened our thinking, have contributed their deep expertise, and have been great company. We also want to thank the oncology fellows who came to Oncotalk and the actors (especially Jeannie Walla) who helped us teach.

The only way to write a book like this is to test our ideas as doctors. We have learned what works (and what does not) from our patients, and we are honored to be part of their lives.

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